Decolonising Health Inequalities: Uncovering the hidden factors behind biological models of Caribbean and African health outcomes in Greater Manchester

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Decolonising Health Inequalities: Uncovering the hidden factors behind biological models of Caribbean and African health outcomes in Greater Manchester

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Psalm 136:1 (New International Version)

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ABSTRACT

This thesis presents qualitative research conducted into an exploration of the hidden factors contributing to the disproportionate burden of disease for people of Caribbean and African descent in Greater Manchester. The study uncovers the hidden factors behind biological models of Caribbean and African health outcomes. It recognises the differences in morbidity and mortality between majority and minority Black groups and how the current evidence base constitutes consistent epidemiological findings of poor health across a range of health measures. The voices of Caribbean and African people were centralised through two phases of ethnographic data collection. Participants shared snapshots of their daily lives which captured their health and social interactions within the health system.

This interdisciplinary piece of work is underpinned by several theories and frameworks and begins by presenting the social construction and post/decolonial legacy of race and its impact on Black people in the health market. It uses the sociological frameworks of Critical Race Theory (CRT) and Kimberlé Crenshaw and Patricia Hill Collins' iterations of intersectionality to explain how through health economic theory, gatekeepers' habitus and the unequal power relationships underpin institutional and systemic decision-making.

Thematic analysis identified themes from the data that exposed external structural biases in the health market with concomitant internal pressures that have post-colonial origins. Findings revealed wide-ranging overarching themes, which were identified throughout the analytical process in phase 2 that had captured and developed themes from phase 1 of the study. Phase 2 themes included Significant Influences on Individuals', 'Discrimination' and 'the Mirror of Black Health'. I conclude that racial disparities in health endure primarily because the foundations upon which racial hierarchies were built are still present and used today.

There has been a fundamental systemic and structural failure across government including public health practices to address the root causes that sustain the poor health of Black people. This study highlights how the deconstruction of race based and discriminatory practices can open possibilities for reconstruction to bring about more equitable solutions in practice-based outcomes. This will require a combination of post and decolonial scholarship, relationship building, health advocacy and political action to mount a sustained communities' campaign for structural change within the health sector.

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List of Abbreviations

Black Majority Churches (BMC)

Black Asian and Minority Ethnic (BAME)

Body Mass Index (BMI)

Caribbean and African Health Network (CAHN)

Cardiovascular Disease (CVD)

Critical Race Theory (CRT)

Department of Health (DoH)

General Practitioner (GP)

Greater Manchester (GM)

Greater Manchester Combined Authority (GMCA)

Greater Manchester Health and Social Care Partnership (GMHSCP)

Human Immunodeficiency Virus (HIV)

Joint Strategic Needs Assessment (JSNA)

Mothers and Babies Reducing Risk through Audit and Confidential Enquiries across the UK (MBRRACE-UK)

National Health Service (NHS)

National Institute Care Excellence (NICE)

Public Health England (PHE)

Quality Adjusted Life Years (QALY)

Sickle Cell Disease (SCD)

Voluntary Community Social Enterprise (VCSE)

World Health Organisation (WHO)

Glossary of Terms used throughout the Thesis

Throughout this thesis, I will be referring to those visibly identified as Black people of Caribbean and African origin. These include those who were born in the Caribbean but whose ancestors originated in Africa or Black people born in Africa. Other terms that may filter within this thesis are Afro-Caribbean, African Caribbean, African, Caribbean, West Indian and Black people who were born in Britain. All of these terms refer to Black people of either Caribbean and African descent.

African

The term refers to Black people that were born (native) in the African Diaspora.

African/ Caribbean- African /Afro Caribbean

The terms are used to refer to people of African ancestral descent and who migrated via the Caribbean islands. The term Black may also be used to describe this individual or group.

Black

A person of African ancestry, who self identifies, or is categorised as Black, African, African or Caribbean or African-Caribbean or Afro Caribbean. I capitalise the word Black[1] when referring to people in this context and do not use the word Black to signify all non-White minority populations. There is a shared history, identity among people who categorise themselves as Black although there are differences between Black communities from the African diaspora and within Africa. The terms Black and Caribbean African or Caribbean/ African are used interchangeable in this thesis.

[1] The capital B describes a race, an ethnic or cultural group, and that is very different from a colours used to describe products.

Caucasian

This term is usually used synonymously with White and it is capitalised when used in this context. I refer to White as everyone who is not Black.

Communities

A term used which recognises that there are several different communities within the defined Caribbean and African community and that being Black is the common characteristic.

Culture

Ethnicity has links to an individual's culture; therefore, ethnicity impacts on cultural beliefs or practices. Culture is a dynamic and fluid process evident in daily practices and values and can change over time and from one generation to the next.

Ethnicity

The social group a person assigns themselves to or is consigned to by others. In this thesis it is based on commonalities such as language, culture, religion. It is used synonymously with race.

Ethnic Minority

This term is used to refer to those in the non-White population. It is used synonymously with minority ethnic.

Mixed Heritage

I use this term to refer to those who have a heritage that consists of Black Caribbean or Black African mixed with another racial category.

Oppression.

Oppression is a historical term used to describe the use of unjust and unfair treatment resulting from a multidimensional imbalance of social, political or institutional power.

Race

Is a historical term used in this thesis to denote a self-identified or assigned individuals to a group based upon a mix of their ancestral physical characteristics such as skin colour and hair type. These characteristics reflect the individual's ancestry and where they were born. Race and ethnicity are often used synonymously.

Racism

It is a social system that reinforces racial inequity with the belief that White people are superior to others. This results in actions less favourable towards individuals or groups based upon their distinct physical characteristics.

Institutional racism

Institutional racism refers to the policies and practices that disadvantage some groups based on their race.

Racial discrimination

I use this to refer to discrimination towards an individual or group based upon their race.

White or Caucasian

A capitalised term used to describe people with European inherited or ancestral origins who self-identify as White. The term is capitalised because White people are also a raced

CHAPTER 1

INTRODUCTION

1. Introduction to the Chapter

Health disparities are deeply entrenched within the Black Caribbean and African communities and these disparities have persisted for decades (Balarajan, 1991; Karlsen, 2010; Smith 2012, Raleigh, 2021). This chapter commences with my aims and research questions followed by the structure of the thesis. Prior to presenting the theory underpinning this study, I provide my personal narrative that outlines the reasons for wanting to do this piece of work. The chapter places my study within a number of theoretical frameworks which is very important to foreground the basis of this thesis.

1.1 Research Aim and Questions

Aim:

This research is principally concerned with the hidden factors that influence the poor health outcomes of people of Caribbean and African Descent. The aim was therefore to examine what it is like to be a Black person accessing health care in an Urban area in Greater Manchester.

Research Questions:

Research question 1: How is public health information understood, made sense of and experienced in the lives of Caribbean and African people in this study?

Research question 2: What do the voices of Caribbean and African people tell us about their health experience and its influence on health outcomes?

Research question 3: What are the perceived (from a communities' perspective) professional health care behaviours and attitudes that produce poorer experiences for Black People?

1.2 Introduction to the Structure of this Thesis

This thesis is organised in to 7 chapters. Chapters 1 and 2 present the background to the study and the literature review of the existing studies surrounding the health of Caribbean and African people. Chapter 3 focuses on the research methodology followed by two phases of data collection in the finding's chapters (chapters 4 and 5). Chapter 6 consists of a synthesis and discussion of the finding's chapters followed by the conclusion and recommendations in chapter 7. Finally, the references and appendices can be found at the end of this thesis.

1.2.1 The Structure of the Thesis

Background to the study

Part I.

This introductory chapter provides a broad background and contextual framework for the study that begins with my personal narrative. I discuss how my story (that includes cultural and religious beliefs) manifested itself in the health of myself, family and friends. The health conditions experienced within the Black Caribbean and African communities are explored and are used as a contextual backdrop to critically present the unequal distribution of poor health. I use sociological frameworks, to present the historical roots of structural racism and draw on Critical Race Theory, and Intersectionality to understand and illuminate the mechanisms by which race impacts upon health.

Part II:

In this section I discuss relevant health economic theories to include an initial theoretical overview of the market and market failures. I highlight some of the health economic frameworks that enable decision-making to take place within the

health system which manages free but finite resources. I explain the concept of gatekeeping and Implicit bias and how these can create barriers to access to the health market for Black people.

Chapter Two: Literature Review

This chapter reviews the literature from an interdisciplinary perspective and critically engages with the findings from themes highlighted in this study. I explore what the literature says in general about the health disparities in Caribbean and African communities within the broader context of decision-making, health, socio-cultural factors. The chapter reviews the extent to which the literature identifies the factors that impact upon the health experience of Caribbean and African people and the context in which the issues have been concentrated. From a review of the relevant literature, I identify the gaps in current knowledge, and this forms the basis of this study. In this chapter, I also demonstrate that there is a lack of research on the historical, structural, systemic and economic factors that impact upon the health of Caribbean and African people in the UK that add to the discourse of health disparities.

Chapter Three: Part 1 - Methodology

This chapter of the thesis sets out the qualitative methodological and philosophical frameworks used to enable the data collection and analysis. In this chapter, I use the origins of ethnography and critical ethnography to uncover silenced voices and marginalised knowledges in the Caribbean and African communities. The rationale for using a Critical ethnographic approach is based upon the need to recognise the power relationships and the impact of policy and practices in Black communities.

I provide the historical context for the emergence of the sociological frameworks of Critical Race Theory and Intersectionality that I introduced in chapter 1. In this chapter I reflexively present critical ethnographical theory using four analytical frameworks which include my position of being Black, a woman, an academic and a health professional. Using critical ethnography as my interpretive framework,

allowed me to understand the participants' lived experiences and its relevance to understanding health disparities. I conclude this chapter by summarising how all these concepts interact with each other to give the analytical framework used to interpret the data that I found.

Part II - Methods

This part of the chapter provides an overview of two ethnographic phases of this study and discusses the practical steps used to collect and analyse the data through each phase. Here, I acknowledge what I call the pre-phase which involves the homework I did as I entered the ethnographic field. The rationale and justification for the approach that I adopted to collect the data is also provided and includes the location for the fieldwork, sampling and recruitment, ethical considerations and the data analytical process. Throughout the chapter, I provide a reflexive account of researcher positionality and how this impacted upon the research process. This chapter also includes limitations of the study.

Chapter Four: Findings – Phase 1

This is the first findings chapter that presents an in-depth account of three main themes that developed from the data using participants' quotes. This chapter presents the research findings without the existing literature in order to hear the voices of the participants. In this chapter, I make reference to my field work diary where my own reflective voice can be heard in line with some of the participants' experiences. My interpretation of the voices from the participants and the notes from my reflective fieldwork diary indicate the challenges that Caribbean and African people experience to address health needs, these are analysed within my stated aim and objectives.

Chapter Five - Findings – Phase 2

The findings during this phase generated further themes that were analysed and presented using participants' quotes to fully understand the nature of the health experience of Caribbean and African people. The 6 participants that took part in phase 2 were also participants from phase 1. This allowed the participants to

explore the themes from phase 1 in greater depth, which generated a further three themes in phase 2.

Chapter Six: Synthesis and Discussion

This chapter unpacks the findings from phase one and phase two of the study with the theoretical underpinning from chapter 1 and locates the synthesis within the existing historical and colonial theory introduced in chapter one. To get to this point, I synthesise both phases and provide explanations for the hidden factors impacting upon the sustained health disparities for my participants. Here, I provide the critical and theoretical commentary that underpins the lived experience of the participants from this study. I provide a discussion which is situated in the existing literature about health disparities in Black communities and identify why Caribbean and African people continue to experience the disparities in health. I highlight how socioeconomic factors, health economic theory, (which explains decision-making by gatekeepers and unconscious bias that leads to market failures) falls short of explaining the reasons behind health disparities in Caribbean and African communities.

Chapter Seven: Conclusions and Recommendations

This chapter brings all the work together along with my recommendations and the implications for future practice in the field. It shows how my own experiences that began this journey with family, friends expanded into the wider communities through my field work. It envisions and illustrates through two impact interventions (i.e. Caribbean and African Health Network (CAHN) and the Mary Seacole Award) how Caribbean and African people can begin to address the structural building of relationships with healthcare professionals and policy makers to improve their health outcomes. This chapter highlights the unique contribution of these findings to the knowledge base and makes recommendations for future work. I end this thesis with my own reflections of this study.

1.3 Part I - Background to the Study

This section of the chapter presents why I was personally motivated to carry out this study. I begin by interweaving my personal narrative using elements of auto-ethnography. I do this despite critiques of this approach, which argue that personal story telling is likely to contaminate and invalidate the results. Critics claim that the anecdotal is subjective and biased and is therefore not legitimate (in) research (Denzin and Lincoln, 2018). However, I argue that for me, this choice of auto-ethnography supports the use of critical ethnography later in the thesis and informs my research rather than invalidates it as biased (See chapter 3 for more details). It also allows me to situate my reflexivity, to analyse and to understand my own experience, to locate and sense-make the cultural experiences within the research that I will be exploring (Holman Jones, 2016).

It is with this auto ethnographical and reflexive approach that I can recognise the importance of 'self' and my positionality about where I stand in relation to others in terms of power relations and what has informed and shaped my identity (England, 1994). See chapter 3 for more details about this. For me, these aspects of the self and identity in my auto ethnography and ethnographic research is significant as I am like some of the individuals in my participant group, Black, a woman and of a Caribbean and African background. The topic of persistent health disparities is of personal and professional significance because the disparities between those from my communities in comparison to those from Caucasian backgrounds continue to widen. I wanted to interrogate CVD because of its personal relevance to me in relation to my experiences and this was captured in chapter 4 findings along with other echoes of disadvantage I experienced in my past. The following section presents why I was personally motivated to study these hidden factors using autoethnography, here I provide an initial micro analysis and description of the experience of a Black Caribbean health seeker in the market using my personal history as a starting point.

1.3.1 The Impetus for this Research – Personal Narrative

I was born in the United Kingdom and I am of African descent with parents that migrated from Jamaica in the 1960's. I am a professionally trained nurse who has undertaken previous work with members of the Caribbean and African Diaspora. In addition, I am a female who has experienced challenges in my personal life, growing up, in my work as a nurse and in my professional career as an academic working in a university teaching on health programmes. All these factors influenced my decision to focus on this topic for my PhD.

The motivation to conduct this study stems from some of my mother's strongest and most compelling memories whilst growing up I remember mum using her own experiences and that of her friends since arriving in the UK to tell me that as a Black woman I had to work twice as hard as White people throughout my education to achieve success. I always remember mum saying, 'if they get a 'B', then you need to get an 'A' plus. The magnitude of what this meant and how widespread this saying was within my communities made me believe that there was some truth in this and therefore eventually conditioned me to adapt my own beliefs to try and succeed. However, working twice as hard to get twice as far did not mean that Black people reached the goal that they aspired to achieve. Here in the UK, we were taught as a family that this was the only way to succeed in White Britain. Whilst researching this, I came to realise that although this saying is predominantly widespread within American literature, this aphorism was also a commonly held principle that identified education as the key to equality and respectability, hence the 'work harder' ethic and the "Politics of Respectability" (Higginbotham, 1993; Dubois,1903).

Against the backdrop of life's struggles, there was an expectation from my parents that I remained strong, persevered and set my aspirations high so that I did not endure the hardship that they and their friends had encountered when they came to live in the UK in the 1960's. These views are echoed from women within my community and in discussions that took place in the community focus groups that I had been privileged to attend as I was doing some work on my current study. I had observed women around me functioning as sole breadwinners; single parents juggling two or more low paid jobs; being carers for their immediate and extended family. In addition to all this, I watched people trying to maintain contact and support their wider communities largely through

the church to gain some sense of belonging. There were so many social problems in families where older children would end up being imprisoned for criminal offences such as drug dealing and robberies. This caused a lot of trauma and stress to family friends. I remember the nights of grief and sorrow as mum and dad constantly received visitors that needed support.

My dad was a Deacon in a large church that he was privileged to help establish not long after they arrived from Jamaica. Most of the congregants in the church were from Jamaica and came to our house sharing fond memories of being back home in Jamaica. However, I remember when I was around 10 years old I overheard one of mum and dad's friends weeping in the kitchen having recently lost his wife. Finding it difficult to contain his emotions he spoke about the difficulty she had when she went to get help from the GP. He said that time and time again she would visit the GP saying that she wasn't feeling well but yet they did nothing but repeatedly sent her away without checking or referring her for another opinion. Mum and dad's friend died in her sleep only 2 days after visiting the GP. She was only 45 years old and left behind 6 young children. Several stories of this nature where people had died, had amputations in their 40's due to unmanaged diabetes were overheard. It was so traumatic for me as a young child along with my siblings sometimes going with mum and dad to visit people in hospital and subsequently attend their funerals. I remember being taken along with my siblings to all night wakes which is the home or relative you visited of the person that had died. Friends and family members would sing hymns until the early hours of the morning supporting the family. Some of mum and dad's friends died young (early 40 to mid-40s) and I was so anxious about my own parents and what would happen to them. They worked so hard for such little pay. My dad worked shifts in a factory and my mum stayed home and worked from day until late at night as a seamstress whilst she continued to look after 7 children. The stressors were phenomenal for my parents who have paid the price with their own health. They were fortunate to have a good network of friends from Church and in Jamaica. They were devoted Christians who would spend a lot of time in prayer and bible reading which they said gave them comfort and strength. At night especially after we had heard of a passing, I could not sleep, decades later I am still mindful of these events. It is only now in my later years that I begin to see the impact that the personal and social stressors that this 'work harder' ethic had on both my mum and many of her friends as they fought against racial, economic and gender oppressions that confined them to certain roles and

positions in society. This point will be discussed further in my chapter 6. The need to suppress my Black identity to adapt to working in predominantly White environments (see Ogbu, 2004 and 'code switching'); to work harder than my White counterparts in order to build a strong sense of purpose to be accepted; has added to the uncertainty of my health status in many ways. The response observed from women within my communities and from the focus groups has been one of frustration, and from my perspective, a frustration that requires interrogating in order to identify its hidden factors and what sustains these health disparities.

School was an unhappy place for me. I was always made to feel that I could not meet the academic requirements. To that end I left school without any qualifications because of the treatment there which was itself influenced by colonial echoes of past behaviours. I signed up to do a catering course and was sent on a placement where my eyes were opened to a new world of university students. It was here that I realised opportunities existed, for the first time. I then decided to leave my catering course and enrol to study and complete three A-levels in a year, despite having no qualifications. I passed my A-levels and went on to do a nursing degree. My desire to do nursing stemmed from past experiences of dismay at the numbers of people in the Black communities, especially in mum and dad's church, that were impacted by poor health largely related to cardiovascular disease. I wanted to do my bit to prevent the trauma that I witnessed around me happening to other children which according to my ongoing life experiences and that of my participants has not improved. Unfortunately, covert racism set in on completion of my training where comments about being a Black woman with a degree in nursing didn't go down very well where a manager of a service decided not to employ me when I applied to her for my first job. Although I am an academic working in a university nursing department now, life has been an upward struggle and for many of my Black nursing students in many aspects. This struggle for support has been from within my own communities as well as from outside, where there has been a competitive type of mentality which only adds to the stressors I have experienced in my professional and personal life.

My journey to where I am now has taken its toll in ways as shared by many of the participants in my study (See chapters 4 and 5). However, I have had many proud moments in my life that include personal and professional achievements. My journey and this study has led me to a place in my life where I have a deeper

understanding of the oppression and the structural disadvantage that I have faced. I can see where and how it happens and I am now able to use this insight as a tool to demand change for myself and others. The construct of race and identity featured in my personal experiences and that in relation to the health of family and friends. I now turn to look at how race was constructed and how this is relevant to the health experienced by Black people.

1.4 Part II - Introduction to My Theoretical Position

The principal aim of this study was to explore the experience of being Black and accessing health in an Urban area of Greater Manchester. I explored the hidden factors that continue to produce poor health outcomes in the Black Caribbean and African communities. It was important for me to set a detailed theoretical context in this first chapter of the study so that the findings were meaningful.

From the outset, I decided to focus on Cardiovascular disease and conditions such as stroke, vascular dementia and hypertension because of the health disparities this disease produces in the Black communities. However, as my study progressed, participants spoke about a significant number of health conditions that challenged them as communities of people. The study uncovers a lack of equal access to the market that can result in poorer knowledge (education capital) of choices and poorer decision-making processes in terms of achieving positive health states. The hidden factors explored are the unseen market relationships between market actors. Using aspects of health economics theory, I redraw the market in terms of its governing relationships between its actors. I show how these market relationships disadvantage Black Caribbean and African people in the health market by examining the role of the ‘gatekeeper’ (i.e. systems leader) and their implicit biases. I present how the differences between the health market and the perfect market, result in market failure and exacerbate the unequal power relationships between health providers and Black people I show how these unequal power relationships culminate in lower health outcomes for Black people. Aided by a selection of sociological and health economic frameworks, I use my experiences as a lens through which to analyse the ethnographic data from my wider study. My interdisciplinary approach foregrounds the market relations of Black communities using critical ethnography which is underpinned by Critical

Race Theory and Intersectionality showcasing the central voice of the study's participants.

1.5 The Historical, Biological and Social Construction of Race

This part of the chapter seeks to bring together an interdisciplinary theoretical framework consisting of coloniality, decoloniality, critical race, intergenerational trauma (epigenetics) and intersectional theories. This framework will help to elucidate the sociological origins of the market failure that will be uncovered in the later part of this chapter. To understand this market failure for the African Diaspora health seeker, it is important that we acknowledge the historical origins of race and its role in helping to create barriers to fully accessing the health market. I will briefly introduce coloniality and intergenerational trauma theories to help outline the historical issues with access to the health market. To provide a framework for the contemporary echoes of these historical biases, I will briefly explore the use of critical race theory and intersectionality. Finally, to introduce concepts that suggest possible solutions, I will also outline how aspects of decolonial theory will be useful to my study.

The interdisciplinary theoretical framework presented in this chapter will underpin the processes of theorizing of both the comments of the study's participants but also the cultural assumptions at the base of decision-making at the policy level.

1.5.1 The historical development of the concept of race

This section of the chapter is framed around scientific racism and polygenism theories forming the bases for the biological models of health. It provides some answers to where the cultural assumptions of these biological models of health originate.

The importance of racial and scientific constructs in the discussion surrounding health disparities rests with its strong influence on how people experience health care. Race and the naming of races became a distinct 17th century idea that dates to the Enlightenment era as European powers set out to expand the colonies. Francois Bernier a French physician in 1684 named 'races' based upon skin

colour, physical characteristics, cranial profile and hair type. These categories sought to privilege or deny people benefits.

Linnaeus (1739–1778), the founder of scientific racism advanced the concept of racial groupings and stratified humans as one species. However, he divided human beings into four distinct sub-groups based upon a typology of physical, intellectual and behavioural characteristics. These groups were classified, and these features were argued to be emblematic of the differences between races. Linnaeus (1739–1778) placed himself at the top of a hierarchical ladder from perfection to the lowest and basic rungs of the ladder. Those classified as non-European which included Black, American Red and Asian were devalued, degraded and classified to be the inferior race or as 'the other'. Other scientists throughout the later centuries such as Morton (1830 - 1851) used comparative cranial skulls among different groups to measure intellectual capacity. These have continued to shape the concept of race into various categories; however, each classification has resulted in Whiteness being seen as the liberal and universal ideal (Blakey, 1999).

During the 19th Century, polygenism became the major model for race theories, which meant that racial differences were rooted in what Galton (1822 -1911) coined the eugenics[2] movement. He considered race and racial classifications at the level of biological differences in the genetic material of each cell. The central basis of this belief is that ancestrally, humans consist of separate species and that race is embedded in biology and genes. Eugenics supports the idea that the differences do not only manifest itself in phenotype or visible physical characteristics in inherited material such as skin colour, but equally within mental, behavioural and intellectual traits (Galton, 1998). Eugenics movements and scientific race theories have attempted to prove that the Black body is somehow inferior to that of the White body and that we needed to be separate. Eugenic and scientific/biological race theories have argued that the differences between Black and White people run deeper than visible differences in skin pigmentation, facial structure and hair type. Beliefs about eugenics can be found in one of the most aggressive programmes, where over 5,000 Black African American women were

[2] Eugenics which means ('good genes) was a scientifically developed theory that sought to increase breeding of what Galton identified as superior genes of White people and to remove all others who were deemed inferior in order to improve the quality of human population with those phenotypes deemed to be of quality and desired.

coerced into sterilisation to reduce the offspring of what was deemed as poor stock (Stern, 2005; Newman, 2018).

More than 120 years ago, 20th century African American sociologist W.E.B. DuBois (1903) wrote '*The problem of the colour line'* which was a response to scientific racism which is still prevalent in the 21st Century (Saini, 2019). Dubois (1903, [2008]) was concerned about the widely held belief by anthropologists such as (Boas 1858–1942) that Black people were inferior to White people at the genetic or biological level for what he understood to be social and cultural differences between different populations of people (DuBois 1903). Although the theory surrounding scientific racism and difference stems back to Bernier and others, this debate has continued to be fuelled by ongoing scientific studies such as the genome project (Collins, 2011) to identify genes that explain the prevalence of diseases along racial lines. Health inequities (and echoes of scientific racism) are seen in many outcomes, across a number of health indicators such as heart disease and mental ill health. A century ago, Du Bois identified that there was a correlation between societal and health inequities and challenged the view that health disparities were a result of racial differences. He noted, "The Negro death rate and sickness are largely matters of [social and economic] condition and not due to racial traits and tendencies" (1906:276).

The idea that human beings are naturally divided into groups that are distinct enough to call them distinct subgroups of the human species has resulted in the practice of race medicine and the belief that variations in health are entirely based upon racial differences, (Bhopal, 1997). However much scientific research has concluded that there is a 1-2% difference between the DNA of humans, and our ape relatives and that the genetic difference between individual humans is less than 1% (Collins, 2011). Despite this, the 1% difference has been enough to oppress some groups in society. This view posits that this difference in genetic material is enough to explain the prevalence of physical, mental, intellectual dissimilarities. Current scientific evidence conflicts with Linnaeus' beliefs about the human DNA and contends that there are more genetic variations within the historically categorised racial groups than there are between groups (Rosenberg, 2002).

1.5.2 The Construction of Blackness and Whiteness

The construction of Blackness and Whiteness is important in the context of habitus gatekeeping (Holloway and Wheeler, 2002) and access to the health market which will be discussed later in this chapter. Habitus is defined as a "structuring structure which organises practices and perceptions of practices" (Bourdieu, 1984:170). We are socialised through habitus and acquire certain habits, skills and qualities that build cultural and social capital from the social networks and connections we have that enable us to navigate our social environments. The notion of Whiteness as defined by the colonists can only be meaningful through the construction of Blackness and this is what lies as the basis for White privilege. Dubois (2008) argues that privilege and high status afforded to White (through their networks) people even for those who were poor resulted in a Whiteness compensation or a "psychological wage". In stark comparison, people with a Black identity were treated more harshly, devalued and received a penalty or "racial tax" for being Black (Akom, 2008). In health, the racial tax can be described as people from the African Diaspora not getting full access to the health market. The wages of Whiteness/racial tax result in economic consequences of limited access to the health market for Black people whilst White people continue to benefit from the health market as the White body continues to be seen as the standard template for assessing health needs, which lies in the National Institute of Care Excellence (NICE)[3] and the Quality Adjusted Life Years (QALY), [4] both of which I will speak about later. Here, it is Whiteness that is the biological template in the medical model upon which many treatments and interventions are based.

This classification of races provided Europeans with an assurance that the system of economic capitalism could be used to enslave people from the African Continent and to generate racial hierarchies that justify their exploitation based on race. As will be discussed later, African Diaspora people have suffered from the ensuing "Coloniality of Power" [5] (Mignolo, 2007) that the phenomena of White privilege and the racial tax describe.

[3] The National Health Service uses The National Institute for Health and Care Excellence (NICE) as a gatekeeping institution to administer the Quality Adjusted Life Year (QALY) as a common measure of quantity and quality of disease and its impact on the (quality of) life lived (Harris, 1999).

[4] QALYs make life and death decisions by measuring and comparing health benefits gained following a health intervention for research allocation or personal medical intervention

[5] Anibal Quijano (2007) a decolonial theorist and his concepts include - The "coloniality of power" is about how the structures of power, control, and dominance have emerged during the

The racial tax has a historical market value because people of African ancestry have been denied products and services in terms of education and health, they have had lower job prospects, which have been quantifiable in terms of cost implications in the economy. Discrimination has economic consequences that can be quantified and given a market cost in terms of health disparities across a range of health measures due to poor access to appropriate care. In relation to health, a racial tax has its links to health economics because the data can show how much more money the system needs to pay to treat Black people but unfairly implies that they are responsible for its different impacts because they did not access the services early enough.

The social construction of race (LaVeist, 1994) has travelled through time and my application of coloniality theory is about describing the historical transformation of this construction of race through time.

1.5.3 Coloniality

The remnants of colonialism are everywhere as it is embedded through our institutions and patterns of behaviour. I argue for decoloniality because there is an assumption that there has been an end to colonialism however, the more accurate word to describe what is currently happening is “coloniality” (Maldonado-Torres, 2016). Coloniality describes systems of power and their dynamics that continue to play a significant role in shaping the structures and attitudes within the UK. I use coloniality to refer to the often-hidden factors that sustain systems and patterns of behaviour that once came from colonialism but now exist as power relations and dynamics shaping how our institutions govern. This is important because the effects of colonialism via coloniality are still being felt by certain groups in society. Grosfoguel (2013) talks about how colonisers committed genocide, “epistemicide” (De Sousa Santos, 2014:92) and the killing of women (as witches) as the kite mark of colonial barbarity – the extermination of people and their knowledges; genocide and epistemicide, respectively. This equates to medicines and modern health care being an ill fit for Black people, as it ignores traditional remedies from communities, their use of which was born out of modern medicines not always generating the best patient experiences for Black people (See chapters 4 and 5 for more details). The colonial killing of women maps across to poor health care of women especially

modern era of colonialism. The “coloniality of power” theory recognises how discrimination is embedded in the structures of postcolonial societies

Black women and childbirth, where they are five times more likely to die from complications to do with their pregnancy (Knight, 2019).

Coloniality can provide an understanding of the impact of power relations and how they can affect health disparities especially when designing and providing care. Quijano (2007) describes the process of colonisation and racial categorisation of African people to achieve what he terms 'coloniality of power'. Quijano (2007) states that the Europeans and Americans used their conquest as proof of their superior status and ground their hierarchical position in catholic, protestant religious doctrines (which supported colonisation) to preach the message of salvation. Their goal was to inhumanely civilise African people who were deemed inferior and with this recognise the power of the coloniser. The 'coloniality of power' (Quijano, 2000) theory is therefore understood to describe how coloniality acts to deconstruct the 'Other' knowledges that exist and the ways that perpetuate categorisation and discriminatory practices that are embedded in the fabric of current day societies. Today, Billingsley (2011) argues that religion and the church act as buffers and play a key role in helping to build the resilience of Black people who are oppressed because of the legacy of slavery and White supremacy.

As coloniality suggests, there remains an unequal balance of power between those categorised into distinct minority ethnic or Black Asian and Minority Ethnic (BAME) groups and those who are racialized as White. "Coloniality of being" (Maldonado-Torres, 2007: 242), which focuses on the "lived experiences and not only in the mind" of the colonised has shaped the way in which marginalised BAME people experience health and is an important determinant of their health (see chapter 3 for a discussion about ontology). As stated above, people of Caribbean and African Ancestry experience disproportionate and higher rates of mortality and morbidity compared to White majority groups in the UK. Through the COVID-19 pandemic, there is notable polarisation of certain populations, including migrants that are disadvantaged by poor, low-paid working conditions and overcrowded living conditions. Through COVID-19, there is evidence of how racialisation is shaping the health experience of Black people. This along with other factors are consolidated by gender, race and class and highlight the systemic structural problems (Fenton, 2020).

Case Example: "Coloniality of Power" in the UK Health System:

The “coloniality of power” is illustrated by the current COVID-19 crisis and migrants who have No Recourse to Public Funds (NRPF): this is described as a system that denies access to Public Funds for people with no leave to remain. Migrants that are more likely to be impacted by NRPF are those from developing countries such as the Caribbean and Africa where Consulate arrangements have not been made outside European Economic Area countries. These places are former Colonies of Great Britain and are members of the commonwealth (which in my opinion is a ‘gentrified’ version of the colonial system) and are being denied this funding. This is an example of “coloniality of power” that is still shaping our institutions and can be described as an extension of colonial violence (Mignolo, 2007; Thomas, 2019). During the pandemic we have evidence of people of colour expected to work in precarious and low paid roles, losing their jobs and not having the ability to claim from public funds. This has therefore subjected them to find work in areas with greater and more frequent exposure to Coronavirus.

1.5.4 Intergenerational Trauma and Epigenetics

Fanon (1965) highlights that the construction of race and the legacy of slavery itself continues to enslave those socially constructed as Black. This legacy continues and permeates the lives of Black people. This imperialistic history (“coloniality of power”) is embedded in the fabric of Western societies and has created a class system between the global North and the global South. Fanon states that “imperialism leaves behind germs of rot which we must clinically detect and remove from our land but our minds as well' (1965:36). Although race is a social construct and not a biological one (Rosenburg, 2002), the socio-cultural impacts upon the individual related to colonial mistreatment is likely to alter the genetic expression of genetic sequences. I interpret Fanon inferring how this trauma can have an impact on people over time, “It is not possible to enslave men without logically making them inferior through and through. And racism is only the emotional, affective, sometimes intellectual explanation of this inferiorisation” (Fanon, 1994:40). Fanons work argues that colonialism was viewed as a domination that was needed to ensure the ‘other’ maintain a marginalised position. He talks about how colonialism sustained violence and oppression.

Building on Fanon’s inference of the chronic impacts of inferiorisation, there is evidence of the lasting deep-rooted effects of slavery, which has created a cycle of trauma that can be passed on generationally. This kind of trauma has been

described as intergenerational transmission of trauma where the impact is felt decades after the initial trauma (Graff, 2014; Shackel, 2018). This interaction of genes with the environment and nature can produce more ill-health and disease causing epigenetic[6] effects to the health of those affected (Hewagama-Mills, 2009, Shields, 2017). The current impact of slavery, colonialism, neo-colonialism has not only impacted those that were directly affected when they were kidnapped from Africa but also their descendants. The legacy of slavery can be felt as argued by DeGruy (2005:121):

> The legacy of trauma is reflected in many of our behaviours, attitudes and our beliefs; that at one time were necessary to adopt in order to survive, yet today serve to undermine our ability to be successful... behaviours that have been passed down through generations.

The Equality legislation is supposed to define Britain as a place that advocates for equality, however, Black people are more likely to be treated in a more discriminatory and unfair way across health, education, criminal justice system, income, employment and housing (Lammy, 2017). Evidence points to how unfair, discriminatory and biased behaviours towards Black people are added up over the life-course and lead to biological and pathological functions that cause our bodies to change and adapt because of the way that we are treated (Williams, 2019). For example, high rates of mental health, anxiety and depression can lead to biological or accelerated ageing or weathering (Geronimus,1992). This means that Black people may carry an allostatic load that subjects them to physiological changes resulting in the underlying health conditions experienced (Geronimus, 2006; Williams, 2019). Prolonged stress places physiological and overwhelming demand on the body. The allostatic load, which is the accumulation of physiological changes that occur because of repeated or chronic stressors in daily life, can result in higher morbidity and mortality (Geronimus, 2006, Williams, 2019). In addition, the biological changes cause Black people to biologically age by 7.5 years (Geronimus, 2006; Williams, 2019).

[6] The study of changes in organisms caused by modification of gene expression rather than alteration of the genetic code itself. Waddington (1942) defined epigenetics as ''the branch of biology which studies the causal interactions between genes and their products which bring the phenotype into being.'

The idea of the effects of slavery and epigenetics can be linked to COVID-19 and the suspected genetic/biological reasons that were initially given for Black and Asian susceptibility. However, it is important to again stress that there are differences between Caribbean and African people in relation to for example COVID-19 where outcomes for Caribbean Blacks are worse than African outcomes (ONS, 2020). The structural disparities around poverty, low socio-economic status, environmental factors have been able to force the genetic code to differently express itself so that it can make some conditions appear like a genetic predisposition (Aroke, 2019). Chronic everyday stressors, whether direct or indirect racism, can cause a change in the genetic expression of individuals leading to high rates of mortality and morbidity (DeSocio, 2018). If we take one example of how this becomes apparent the evidence can be seen in the stark disparities shown in high mortality resulting from pregnancy where Black women are five times more likely to die in pregnancy or shortly afterwards from complications (Knight, 2019). The babies of Black mums have a 121% more chance of stillbirth and 50% higher risk of neonatal death (Knight, 2019). The disparities continue with Black mums more likely to have a pre-term birth (Li, 2019) and a recent study of 4.6 million women across 7 countries also highlight the 43% higher risk of miscarriage in Black women (Quenby, 2021). This link can help to highlight how generations of slavery and poor childhood experiences can expose children to intergenerational toxic stress that impacts upon their life-long functioning. Schofield (2019) attributes racism and discrimination as the causes of the sustained challenges to Black people's physical and mental health over the generations even when not directly subject to a racist or discriminatory experience.

Despite Black people not directly experiencing a traumatic event, certain conditions like mental ill-health can result from Post-Traumatic Stress Disorder[7] which can be traced back generations. However, DeGruy (2005) did not accept the term Post Traumatic Stress Disorder but directly wanted to address Post Traumatic Slave Syndrome (PTSS) among descendants of Black slaves. DeGruy (2005) argues that the form of oppression experienced by Black people during slavery and institutional racism can result in collective multigenerational trauma and grief which can be directly or indirectly experienced by Black people. The

[7] Post-Traumatic Stress Disorder (PTSD) is the psychiatric disorder that can result from the experience or witnessing of traumatic or life-threatening events such as terrorist attack, violent crime and abuse, military combat, natural disasters, serious accidents or violent personal assaults" Iribarren 2005 Dec; 2(4): 503–512Post-Traumatic Stress Disorder: Evidence-Based Research for the Third Millennium

consequences of these stressors are difficult to repair as Frederick Douglass quotes, "It is easier to build strong children than to repair broken men" (cited by Mapp & Gabel 2019: 145). These chronic stressors can influence the individual over the life course and this can impact greatly upon their physical, intellectual and emotional development. This can for example lead to miscarriage which costs the UK economy £471 million each year (Quenby, 2021) and other pregnancy related complications.

Earlier on, I shared my personal experiences and reasons for doing this study, I relate to many of these stressors which included the internal conflicts that I had growing up. DeGruy (2005) makes reference to these behaviours and attitudes and the relevance to the historical chattel slavery that Black people endured that made them more likely to adopt associations of ongoing oppressions. This created elements of disharmony amongst Black enslaved people and refers to what my participants alluded to when they were talking about those that would try to hold back progression of Black people in their own communities (Owusu-Kwarteng, 2017). However, as I look back, this form of generational normalised behaviour took place in many Jamaican households and can be traced back to chattel slavery where people were stripped of their identity, culture and family (DeGruy, 2005). Colonisers treated African people like animals in violent beatings and abhorrent ways and the barbaric behaviour of the overseer was internalised by the enslaved. Some of these stressors have led to psychological scars, which results from a lack of identity and not being rooted.

Health inequality across a significant number of health indicators are pervasive for people of Caribbean and African descent and the effects of colonialism does not disappear with the generation that has experienced colonisation. The next section leads me to discuss the centrality of race and its role in public health.

1.5.5 Critical Race Theory (CRT) and Public Health

My use of CRT is about centering the voice of my participants in telling their own stories. CRT is being used as a tool to help make sense of the contemporary experiences of injustice of the participants. CRT is used in my ethnography to foreground and value the lived experiences of my participants. CRT is a theoretical

concept with five tenets[8] created in the 1970 and 1980's by critical legal scholars to challenge the racially unjust legal system and articulate a discourse that focused on issues surrounding race and racism (Crenshaw, 1989).

It is a concept that has its roots in Critical theories of race which stem back to the mid-19th century activists WEB Dubois and Frederick Douglass. Scholars such as Dubois (1868 - 1963) and Douglass (1817–1895) recognized the biased mechanisms by which legislation subjected Black people to inferior socio-economic conditions and unfair treatment (Delgado & Stefancic, 2017). Douglass (1854) (as cited in Darby, 2018:43) states:

> The whole argument in defense of slavery becomes utterly worthless the moment the African is proved to be equally a man with the Anglo-Saxon. The temptation, therefore, to read the Negro out of the human family is exceeding strong.

CRT discourse is used in education and other fields to critique and expose socially constructed beliefs and stereotypes about race and racism and how they create inequality in those fields (Crenshaw, 1991; Gillborn, 2015). Gillborn (2006) discusses CRT as an examination, which describes how everything is set up in favour of White majority to the exclusion of everyone else. Gillborn (2006) highlights that racism is so covert and embedded that it almost becomes invisible (but still maintains its coloniality). The systemic factors that can create disparities have been fairly silent (hidden) despite the opportunity to utilise a CRT framework to provide a lens through which the root causes of health disparities could be examined. Although long overdue, the Marmot review (2020), ten years on, recognised race as a social determinant of health. However, this review only documented racial disparities and its impact on health. The review, in my opinion did not go far enough to identify the relationship between race, racism and the complexities surrounding power. It did not identify in detail the multiple influences racism has on the policies and practices that bring about the health disparities we see for people from the Caribbean and African diaspora.

[8] There are five major tenets of CRT: (1) the notion that racism is ordinary and not aberrational (2) the idea of an interest convergence change happens when it also benefits those with privilege (3) the social construction of race - (4) the powerful idea of storytelling and counter-storytelling to unlearn untrue beliefs; and (5) the notion that Whites have actually been recipients of civil rights legislation (Hartlep, 2009:6)

CRT enabled my participants to express what is usually hidden and this constitutes the 'hidden factors' that I wanted to elucidate in my objectives. Critical race scholars (Delgado, 2017; Williams, 1995; Ford, 2010) argue that racism exercises a "coloniality of power" that is so toxic that is yields health disparities based upon racial categories placed upon people based on phenotypes. They argue that the way to reduce health inequities is to develop new structural practices that respond in ways that eliminate structural racism.

Public health is an objective science that has the remit to promote health and prevent disease, however, for me, this is the opposite approach to that adopted by CRT (Airhihenbuwa, 2018). Knowledge production through story telling (see chapter 3 for my version of 'knowledge co-analysis') is one of the tenets of CRT and targets the ways in which covert and systemic racism operates to disadvantage Black people (i.e. addressing the "coloniality of power"). The remit of CRT is therefore to centralise the voices of the oppressed and to seek out experiential knowledge from vulnerable communities to change, eliminate and transform the poor outcomes of health for Black people (via decolonial thinking, which I will outline later). However, knowledge has been traditionally produced by western thinkers that devalues Black voices and promotes the voices of the powerful (Elabor-Idemudia, 2011). The lack of these voices has made it difficult to address issues affecting Black people because public health knowledge is constructed and shaped through the eyes of a colonial education system (Verweijen 2020). For me, it was important to hear the voices of my participants and uncover the hidden practices to bring about justice and fairness. Although racism is relevant to public health, this field of health care and research in the production of knowledge has largely ignored how relevant this is when addressing health disparities in the UK

1.5.6 Intersectionality and Health Disparities

At the intersection of gender, race and class there is an oppressive and dominating system that manifests itself in hierarchical power relations that is socially constructed. This system creates a power struggle where one group gains control over the other because from a societal perspective there is more value attributed to one group over the other (Weber, 1998). This system is one of the most notable social divisions in civilised societies creating disparities because of the way in

which resources are distributed and allocated based on intersecting identities. Throughout this study, I use the intersectionality framework because it can help to theorise the contemporary experiences of health in the field of public health. The 'modern gender system' is a product of history and intersects with race, class and colonialism (Lugones, 2010) which can be seen in the way Black women for example experience maternity care. Lugones (2007) argues that the "coloniality of gender" comes from the intersection of race and gender in relation to its structures and how they are set up. Quijano argues that all power is structured in relations of dominant, exploitation and conflict as social actors compete for control of "the four basic areas of human existence: sex, labor, collective authority and subjectivity/intersubjectivity, their resources and products" (Lugones, 2007:186). What is characteristic of global, Eurocentered, capitalist power is that it is organized around two axes that Quijano terms, "the coloniality of power" and "modernity" (Quijano, 2007, 168).

As mentioned earlier, colonialism is still part of our present and a system that creates a power struggle where one group gains control over the other because from a societal perspective there is more value attributed to one group over the other (Weber, 2010). This system is one of the most notable social divisions in 'civilised' societies creating disparities because of the way in which resources are distributed and allocated based on intersecting identities. I will briefly outline how Intersectionality and "coloniality of gender" (Lugones, 2008) are closely linked. Intersectionality is a concept introduced by Kimberlé Crenshaw and recognizes the multiple disadvantage of African American women that cannot be understood by adopting issues around race, gender and class as separate entities (Crenshaw, 1989).

Intersectionality in this study provides a framework to explore how the underlying systems and processes shape the health experience for Black women and men. Intersectionality is broadly understood as the intersecting identities between gender, race and other categories. These identities interact and impact on the lives of individuals resulting in an inter-related interplay of processes that serve to advantage or disadvantage people through hierarchical systems of power (Collins, 2000). The matrices of domination developed Collins (1990) argues that to understand oppression we must understand privilege. She describes four

interrelated domains[9] that organise power relationships in society. Collins (1990) contends that we cannot fully understand oppression without appreciating the ways in which privilege can create oppression. The role of power impacts upon individuals dependent upon where the intersections meet and for Black women, there are many ways in which the four domains (i.e. structural, disciplinary, hegemonic and interpersonal) can impact upon the measures of health (Collins & Bilge, 2020). I use Collins' (1990) matrix of domination to outline and identify, through lived experiences, how people can be affected by the structures, policies and practices that occur within health and how this impacts health disparities. There are many examples within the health care system where an intersectional approach to understanding stereotypes would be beneficial for African Diaspora women. There are health-damaging stereotypes that have stemmed from slavery through to the current day where Black women are socialised by their parents and communities to be 'strong Black women' (Cole, 2018). Black women are more likely to be viewed as promiscuous and highly sexualised single mothers with many children (Rosenthal, 2016). These stereotypical ideologies continue based on the view that Black people are uncivilised and deserving of being dominated and treated in inhumane ways. These behaviours subjected many women (who were classified as 'property') to slave owners to sexual acts with White men without consent. The current systems of oppression have been used to marginalise and justify the treatment of Black women, which can greatly impact on the health of Black women (Collins, 1990; hooks, 1981). There are many examples of this in maternity care in the UK and US where Black women experience substandard care due to stereotypes and assumptions of 'the strong Black woman.'

Intersectionality offers the opportunity to explore the ways in which disparities are impacted by power and provides an opportunity to identify ways in which power can be deconstructed and critiqued (Collins, 1990). Although the development of intersectionality theory has focused on women's experiences, it is worth identifying the significance of (multiple) intersecting identities of Black men (See chapter 7 for more details about the 'multiple identities' of the Black male). Overall, there is a general view that men are associated with several privileges, however, there are historical and oppressive stereotypes that create disadvantages and a lesser view

[9] Patricia Hill Collins (1990) conceptualises the matrices of domination consisting of four domains in which power is theorised: structural, disciplinary, hegemonic, and interpersonal. The framework of the matrices of domination gives voice to Black women who are at the margins in America

of the Black man (Curry, 2017). Historically, Black men are associated with racist stereotypes of being immoral, aggressive, bad, dangerous and violent and are 'othered' as Black women. These stereotypes justify disproportionate killings and targeting of Black men by institutions such as the police and harsher sentencing by the criminal justice system compared to that received by other groups. The recent killing of George Floyd is a historical and regular occurrence that can be traced back to colonialism and the lynching of Black men during the Jim Crow era in the US (Jones, 2005). George Floyd sparked a heightened resurgence of the Black Lives Matter movement where the brutal killing shone a light globally on the mistreatment of Black people across the world (Garza, 2020). These racial micro-aggressions[10], discrimination and disregard for the Black male body impacts upon the overall health of Black men subjecting them to high rates of mental ill-health and overall poor health (Jones, 2005). The prevalence and de-prioritisation of targeted prostate cancer treatment, harsher treatment in the mental health system with drugs and not talking therapies and the lack of targeted HIV treatment in the Black African communities are all examples of de-prioritised care.

The need to display masculinity is shaped by different historical and cultural contexts where Black men feel the need to fulfil positions of cultural (tribal) authority, strength and to display the perception that they are 'cool' and do not need support (hooks, 2004). So much of this has stemmed from the shame and degradation of chattel slavery where they were subjected to such harsh treatment. This has resulted in repressed internalised anger, low self-esteem, communities' disharmony, stigma, shame and this idea that Black people have less worth (DeGruy, 2005).The legacy of slavery has resulted in a 'crab in a barrel' syndrome where Black people lack support for each other, where there is Black on Black killing and also where others have held White women as the model of beauty (Yan, 2014). Some of the negative legacies of slavery have been internalised as DeGruy (2005) recognises such as self-hate, anti-African sentiments and not being proud of being Black, which can manifest itself in Caucasian ideals. This internalised behaviour can be passed down intergenerationally. DeGruy (2005) argues that Black people should view their behaviours and attitudes through the colonial lens of history to understand the impact and influence of slavery on Black people attitudes today.

[10] Racial microaggressions are everyday, intentional or unintentional verbal and non-verbal behavioural expressions that communicate hostile, derogatory, or negative racial slights and insults to the oppressed target person or group (Sue 2007:271).

The legacy of post traumatic slavery syndrome has in many ways contributed to the continued poor engagement of men with services. For example, Black men are less likely to participate in prostate cancer screening because they need to be depicted as strong tough and masculine men who do not subject themselves to an invasion of their privacy (bodies). In addition, the mental health needs of Black men have not been addressed as Black men lack trust of professionals and refuse to encounter the very services that they believe has subjected them to oppression and racial injustice.

Critical ethnography provides the opportunity to challenge, disrupt and bring about justice and equity through the unheard voices and experiences of Black people impacted by intersecting disparities and bring new knowledges. Through critical ethnography and an intersectional lens these knowledges can directly contribute to policy agendas such as the 2030 Agenda for Sustainable Development to drive change for Black people. [11]

1.6. Part III – The Health Market

This next part of the chapter provides an overview of the market and decision-making in health. I have decided to focus on this because it is important to identify the mechanism by which decisions are made and the impact that this has on health disparities. I do not attempt to highlight all economic aspects but to only take a selection that I find particularly relevant to this study.

1.6.1 Historical Overview - Concept of the Market

The NHS health care market is unlike any other market where there is power and autonomy to choose and consume goods and services. These assumptions cannot be made in health care as it is a merit good[12] and largely provided free at the point of consumption. We do not know how much health benefit is produced from health care because health is dependent and influenced by other social

[11] This is a United Nations call to action to end poverty, protect the planet and improve the lives and prospects of everyone across the globe (UN, 2020)

[12] Merit goods are commodities that the public sector provides regardless of the ability to pay because they are likely to deliver positive externalities for the social good which exceeds the private gains Pigou (1920) The Economics of Welfare. They are those costs or benefits that produce a third party negative of positive effect through consumption of goods).

determinants which include race (Marmot, 2020). Earlier in this chapter, I spoke about the experiences of some of my family and mum and dad's friends who suffered poor health because of those social determining factors such as low income, poor and overcrowding housing. These things meant they lacked health knowledge which impacted their access to timely and appropriate health care.

My reading of the market is about uncovering its hidden market relationships and their impact on the health-seeker market in terms of how resources are allocated. Alfred Marshall's (1919[1920]:113) "social credit" idea strongly points towards relationships between market actors and implies that the market is crucial for creating the space for these relationships (Swedberg, 2009). Economics is a recognised discipline that involves the use of a set of micro and macroeconomic tools to make decisions based on scarce resources (Sloman, 2010). It is concerned with choice and the management of those scarce resources that exist due to the infinite nature of human wants versus insufficient or finite resources to produce the goods and services that are demanded. The market therefore seeks to find the best ways to use and manage those limited resources.

1.6.2 The Closed Market

When considering the general economic principles of market economics, most market definitions in modern capitalist economies are understood to contain two main elements where two or more buyers and sellers whether individuals or businesses interact to facilitate an exchange of goods or services (Mwachofi, 2011; Heyne 2014). This transaction can take place on a national or global level or in a physical space or virtual environment (Clennon, 2015). Although the salient features of free market economics are based upon the principle of individuals or businesses trading goods and services, markets are often classed as having mixed economies. Essentially, the neo-classical approach[13] to economics states that markets should be free from government interference and as such are built on the forces of free competition or the 'perfect market' and the medium of exchange (usually the equilibrium price) is determined by an interplay of supply dictated by the demand in the market. So, for example, the value or price of the

[13] Neo classical approach assumes rational, utility-maximising behaviour by agents with given and stable preference functions: focuses on attained, or movements towards, equilibrium states, and is marked by an absence of chronic information problems (Hodgson 2007: 236).

resource is based upon how scarce the resource is and how many people demand the supply of that resource.

The mechanisms of market competition are accepted as tools to enable suppliers to achieve the most favourable market price for their products or services. In healthy market competition, no single or group of suppliers or consumers can command how the market will operate or determine the price or rate of exchange for their goods and services. However, market competition in the UK does not exist as an abstract (or as a "perfect market"). Modern capitalist systems rely on the role of government to provide certain basic public goods at low costs and provide a competitive playing field by implementing legal and regulatory rules (note that Adam Smith (2012 [1776]) was against government intervention in his seminal treatise, *The Wealth of the Nations*, where he laid out the role of the "free market" in early capitalism). However, this modern idea of government intervention and regulation comes from Keynesian economics and states that governments need to intervene in periods of unemployment because the market would not naturally balance itself to create the jobs needed (Keynes, 2018). In the health market, this argument is idealistic because it is based on the principle that health care is the perfect market and meets the conditions for efficient resource allocation in the perfect market. In publicly owned healthcare systems, the conditions that define the perfect market are not met and market failure results.

In perfect market allocation, price setting is about the relationship between the buyer and the seller and who has the power to set that price (Mwachofi, 2011). This is linked to Marshall's (1919[1920]) 'social credit' (113) in terms of his description of the "fiercest and cruellest" (256) competitions that are found in a closed market (where 'social credit' can break down). However, where there exist monopolies and oligopolies, in perfect market competition, as described by Smith (2012 [1776]), there are no running costs, controls or restrictions. In the 'perfect market', buyers and sellers can enter the market freely and set their own price largely determined by the supply and demand needed to establish market equilibrium. In addition, there is no waste and the products in the market are transparent and mobile. In the health market, the reforms to contain costs have seen a trend in the rise of gatekeeping roles that have been charged with decision-making. For example, one of the gatekeeping roles to manage resources is grounded in econometric measures that define quality based upon 'desirable' health states. Gatekeepers or system leaders in health care include Department of Health, National Institute and Care Excellence (NICE), Clinical Commissioning

Groups (CCGs), General Practitioners (GPs), dentists or individual clinicians. Gatekeeping agencies such as the National Institute of Care Excellence (NICE) are left responsible for using two crude measures (Harris, 1987) or components of quantity and quality for making decision and containing cost. Measures used to determine 'who gets' and 'who does not get' can result in disadvantage to some groups in society. Decisions about what NICE will and will not approve are obviously underpinned by health economics. Rawls (1973) argues that the principle of justice requires that there is a fair and equal distribution of resources. Justice therefore implies that we all regardless of who we are have equal rights to goods distributed based upon analysis of the benefits. Here I reassert health care as a human right not a commodity.

NICE use a conceptual framework that utilises tools such as Quality Adjusted-Life Years (QALY's) and Disability Adjusted Life years (DALY's). QALYs make life and death decisions by measuring and comparing health benefits gained following a health intervention for research allocation or personal medical intervention (Benson, 2017). They are particularly focused upon effectiveness, efficiency (value for money) and the cost health interventions incur to guide health care resource allocation. QALYs place a value or measure upon each health state based upon quantity (life expectancy) and quality of the individual's life that takes into account that throughout the lifespan, individuals move through different functional states of cognition and the ability to independently carry out activities of daily living pain free. Estimates using the health utilities index are made of years of life remaining following the outcome of treatment or intervention and each individual is given a score on a scale from 1.0 to zero where 1 equates to one 'perfect' year of life and zero equals death. Various forms of health state valuation are used to determine how many QALYs a year of life in a given health state generates (Whitehead, 2010).

1.6.3 Health Markets, Institutions and Sociological Concepts of Power

Thinking about markets as 'social institutions' (Coase, 1988; North, 1990) allows us to draw upon the sociological concepts of power and control, which dovetail with my previous discussion about Coloniality. Although Foucault's powers will be described later on, I specifically highlight the work of Bourdieu and its relevance in this discussion because 'habitus' and 'field' is the main function of the gatekeepers

and access to the market. I will now briefly outline the Bourdesian constructs of capital, habitus and field to conceptualise a number of issues such as the idea of market power and relationships. Drawing on the work of Bourdieu (1977) the relationship between structure and agency is viewed as a "power system" or involved in the "mediation of power", (Giddens, 1985). Habitus is a concept developed by Bourdieu (1984:170) who describes it as "a structuring structure, which organises practices and the perception of practices". Bourdieu refers to our different behaviours that are shaped by the structures we live in, whilst Collins' (1990) matrix of domination could be viewed as a method of organising these (overarching) societal structures. Although these societal structures are not fixed, they can be sustained and transferred from one context to another. They can do this using habitus, where it is a system within our societal structures that consists of the way we do things, our habits, skills, outlook and responses we have to the world around us (Wacquant, 2005). Our behaviours and attitudes reflect those of particular social groups within particular social classes. In Bourdieu's (1977) work on habitus as an exclusive 'club' that makes it owns rules and decides its own traditions and capital, Bourdieu (1990) can be seen to analyse how markets work, if we use habitus to interpret the controlling and determining power structure of the market, now viewing the market as a "field". For example, Ham (2013) describes the NHS as a highly institutionalised field and as such, it can be resistant to change. For Bourdieu (1984:3), he argues that this is based upon the rules within the field which has its universal "eye" where everything is socially normed to conform to a particular way of thinking. For example, Lin (2002) argues that in order to be appointed into some roles you need to be part of a club or a network and progression is based on social capital in relation to who you know and who knows you rather than experiences, skills and qualifications (i.e. cultural capital). This is important because in these social terms, we can see that habitus (field) is built on Marshall's 'social credit' idea that described how trade was made easier between sympathetic market actors.

Bourdieu (1977) presents some key contributions to the exploration of the varying forms of power in society and argues that markets have been governmentalised progressively within public institutions such as health care. This is important because whoever controls the market in terms of power, can create scarcity.

In general economics, the market is concerned about how resources are allocated based upon price, willingness to pay and the distribution of output as only those who are willing and able to pay the price have access to the resource. The view of

health economics relates to the application of economic approaches (as outlined, previously) to questions regarding health, which are primarily concerned with the allocation of scarce resources. There is scarcity in the supply of health care resources and an ever-increasing demand for health care that Arrow (1963) historically and formally linked the discipline of health economics as a subset of economics. In response to scarcity, rationing is a process of limiting the use of all possible health care services and is not only carried out on the basis of price, but on the basis of delay (waiting times), by deciding not to provide certain services, and on the basis of health outcomes associated with the service or intervention (Klein, 1996). This forms the basis of the resource allocation framework that comprises; welfarism, extra-welfarism and capability, which I will explain, below.

1.6.4 Welfarisim

Keynes (1883) and Robbins (1932) influential economists for Beveridge's thinking and his 1942 report in relation to health care, saw that the State had a responsibility to keep people well by protecting or rehabilitating their capacity to work to continue to grow the economy. Welfarism considers each individual and the amount of utility gained by an intervention (Culyer, 2012). In welfare capitalism, the development of health economics largely influenced by the health care system is shaped within an economic, political and social context. This level of welfare is measured using value judgments based upon the principle of pareto optimality [14]and seeks to allocate resources efficiently even in budgetary constraints. The aim is to bring about benefit to everyone in society because the outcomes gained outweigh the costs of the intervention rather than the costs being more than the outcomes. If the costs outweigh the benefits, then it will lead to other needs that will not be met. This can be framed within Bourdieu's (1994) thoughts about habitus (or field) which links to gatekeeping that I will discuss later on in this chapter because it is relevant to decision-making in health care.

In the UK, health care systems are subject to many challenges due to demand for scarce resources, rising costs, new and more efficient technology. These challenges present more demands for those resources and decisions need to be

[14] "Pareto optimality is an analytic tool for assessing social welfare and resource allocation developed by Italian economist Vilfredo Pareto (1848–1923). An allocation is considered Pareto optimal if no alternative allocation could make someone better off without making someone else worse off" (Mock, 2011: 808).

made to manage that demand. Pareto optimal resource allocations are therefore formulated by value-based judgements regarding what is equitable and 'unjust' (Whitehead, 1995) which are used to determine how scarce resources are allocated. Welfarism is the foundation for cost benefit analysis (CBA). However, there are limitations of this approach in relation to CVD, for example. One of the limitations of the welfarist approach is that it focuses mainly on individual's utility or satisfaction and does not take into account what is called the evaluative space (health).

1.6.5 Extra Welfarism

The above limitation led to the development of extra welfarism to address the issue of evaluative space. Extra- or non-welfarist (Culyer) approaches to health have changed the evaluative space (that is, what is to be valued in an evaluation) within economic evaluation away from utility and towards a broader space that can contain capabilities and characteristics, including, for example, health. As such, extra welfarism is the foundation for Cost utility analysis where Quality Adjusted Life Years (QALYs), is used (Coast, 2004). However, an important question here is: what rules are used for decision making that are applied within that evaluative space

The pressures that economists deal with when analysing and evaluating finite resources in terms of what services to fund (individuals, governments, companies) often result in choices, derived by comparing the costs and benefits of alternative resources (Drummond, 2015). These decisions often end up in necessary and inevitable trade-offs regardless of any inherent value-system that we assign to the decisions. I will discuss QALYs later on in the chapter in more detail, where I will outline the equity and efficiency 'trade-off' discourse. Utility is associated with the consumption of goods and services and the consumption of leisure time, how much of this do I have and how does society help me to maximise my utility. Whatever I consume should result in a utility. Within health services are some of the many goods that can be produced and the consumption of these health services results in utility that may for example be because of health information/education or use of services.

Despite the application of the same micro and macro-economic tools used in general market theory such as supply and demand, Arrow (1963) and Pauly, (1968) and as echoed by Olsen (2017) distinguish the branch of health economics

as different from other markets. Arrow (1963) in his paper on 'Uncertainty and the Welfare Economics of Health care' demonstrates that health care cannot be traded like other products and services. He states that health care is not a marketable product and is different to other goods and services and therefore cannot meet perfect market conditions. Arrow (1963) illustrates this by using as an example, the certainty that a clothes factory will produce clothes as an output, whilst in contrast, there is less certainty that the health care industry will produce health as an output. This is due to the interdependent factors associated with health outcomes that are unpredictable and that are based upon probabilities prior to the intervention, upfront costs and the focus on health as a merit good because consuming it may bring benefits to the individual and also to others. In addition, the outcome of the health care intervention is almost always dependent on social bonds (i.e. 'social credits) with other factors such as lifestyle change, ability to self-manage or self- care, making it difficult to determine prices, quantities and resource allocation. As such, the market forces of supply and demand (as seen in other markets) for health care reduces the ability to determine the allocation of scarce resources.

1.6.6 Capability

The capability approach developed by economist Amartya Sen (1993) is a theoretical framework that has two claims 1) freedom to achieve wellbeing is most important 2) that freedom to achieve depends upon the individual's capabilities and whether they want to be valued within the scope of the opportunities (Sen, 1979). Capability approach is offered as an alternative to the QALY because the QALY focuses on the value attributed to quality of life measures and does not provide the evaluative space to address interventions that improve people's quality of life beyond health years gained. The capability approach takes a broader view than the QALY because it recognises the value of health interventions that provide outcomes not directly associated with health. These include for example the benefits of participation in social and wellbeing activities and how people can become empowered. A number of authors have advocated use of the capability approach as a preference to the QALY (Coast, 2004; Anand, 2005). Sen (2010) considers the barriers to translating or developing resources into capabilities by individuals who may be marginalised, vulnerable or of socio-economic disadvantage. These could therefore create health disparities because they could

impact on the individual's ability to function and therefore convert commodities into capabilities. But, what does the capability approach tell us about how scarce healthcare resources should be allocated, and how do we go about using the approach to enable that translation of resources into capabilities? The capability approach is also at risk of the same moral dilemmas as the QALY in that there is still a decision to be made about the allocation of resources and how this translates into capabilities. Who determines that?

1.6.7 National Health Service (NHS) Market

NHS reforms have moved towards a competitive and regulated market commencing with the 'internal or quasi, market between 1991 and 1997. This form of market-based competition in health care provision was introduced as a way of reaping some of the intended market benefits realised in the free market such as, increased efficiency, choice, improved quality, innovation and provider responsiveness.

For the NHS, this meant that the internal or quasi market resulted in the decentralisation of funding to GP commissioners who were responsible for buying, selling and managing services from competing providers on behalf of their local population. Amidst this reorganisation, it was envisaged that the competitive nature of health care provision between providers within the internal market would result in a more responsive and high-quality service ((Fotaki, 2010; Propper, 2012) due to the increased incentive for health care providers to win contracts.

Subsequent reforms in 1997 led the then elected Labour government to focus on reducing competition and concentrated on mechanisms whereby there were cooperative relationships between buyers and sellers negotiated over price and quality, such as waiting times. Although the internal market has brought about benefits such as reduced waiting times, the NHS is a sponsored and controlled monopoly in that the market for health. This is fixed via the state and consumers cannot go to the market and purchase healthcare, as consumers can do in a free market (Propper, 2012). In health care, not only is the number of sellers (i.e. health providers) intentionally restricted access but the infinite number of buyers (i.e. Individuals) that do not have the option to exit the health care market because at some-point everyone will need to use health care services (Mwachofi, 2011).

1.6.8 The Market and the NHS as Social Institutions

The National Health Service uses The National Institute for Health and Care Excellence (NICE) as a gatekeeping institution to administer the Quality Adjusted Life Year (QALY) as a common measure of quantity and quality of disease and its impact on the (quality of) life lived (Harris, 1987). It is probably one of the best used examples of utilitarianism [15] in that it makes decisions following calculations of QALYs that decide which interventions should be given. QALYs place a value or measure upon each health condition based upon quantity (life expectancy) and quality of the individuals' life that takes into account that quality throughout the lifespan, where individuals move through different functional states of cognition and the ability to carry out activities of daily living pain free. Estimates using the health utilities index are made of years of life remaining following the outcome of treatment or intervention and each individual is given a score on a scale from 1.0 to zero where one equates to one 'perfect' year of life and zero equals death. The QALY questions which intervention should be given to which patient by a QALY calculation and considers how many more years the patients will live, it questions the quality of their life during those years, and what how much it will cost for each QALY.

Whilst Bourdieu's analysis of the market focuses on institutions as a field and gatekeepers, which are particularly relevant to my study, Foucault identifies how institutions control the gatekeepers in terms of defining Power and how it is exerted. Foucault describes three different types of Power (law); juridical, discipline and bio-power. Juridical power which is how the state uses laws to regulate peoples' behaviours is a similar concept to habitus but habitus is even more relevant because it is more applicable to the field and the gatekeepers I was exploring. However, here in relation to social norming, Foucault's discipline power questions whether the buyers and sellers in the market (or the social institution) are socially conditioned or institutionalised to accept the power structure of what the market can do and does do and the imbalances within it. This is important because this defines how the market forms its mechanisms of exclusion based on the "just" concept. With Foucault theorising how the market engages the individual

[15] Jeremy Bentham (2017[1823]:7) one of the architects of utilitarianism (along with John Stuart Mill (1863) writes that "'utility' is meant the property of something whereby it tends •to produce benefit, advantage, pleasure, good, or happiness (all equivalent in the present case) or (this being the same thing) •to prevent the happening of mischief…, pain, evil…, or unhappiness to the party whose interest is considered.."

to accept the rules of the market, these are theorisations of the hidden market processes of relationship building which my study is about.

In the health care system, this can be illustrated, from a public health perspective where Armstrong (1993) argues that public health strategies are simply a way of exercising medical power through the surveillance of population's health behaviour. Armstrong (1993) argues that public health interventions are not just something that occur because of policy but because of state interest and goals. Here, Armstrong's surveillance of populations' health borrows from Foucault's "bio power" that alludes to how states govern their populations (biologically via controlling deaths, births etc) and how citizens are institutionalised to accept these controls through his "discipline power". This explains the "fiercest and cruellest" social bonds in a closed market (social institution) which on one level can exclude a certain type of health seeker via gatekeeping implicit bias but on another level where population rates are concerned, the state seems unwilling to control certain demographic morbidities despite collecting the data from their surveillance!

Foucault (1979) also presents some key contributions to the exploration of the varying forms of Power in society, as he argues that markets have been increasingly governmentalised through regulation and centralisation within public institutions, such as health care. This can be illustrated through the medical dominance of Power and knowledge, through the proliferation of medical managers and the bureaucracy of the health system (Foucault, 1979). Foucault states that Power retains its status as Power by proliferating different types of knowledge, but each type of knowledge needs an administrator or functionary to administrate it; this then results in a highly bureaucratic organisation potentially resulting in too many managers. Therefore, and in my view, managerialism can become fertile ground for implicit bias, (this idea of implicit bias which could be said to be the site of coloniality, will be discussed later on) where biases are unconsciously built into the systems that are being managed. In this way, the institution keeps the power in the hands of the health institution. This powerful positioning can directly impact upon how people seek help and often this experience or anticipated feeling of disempowerment can stop people engaging in health prevention activities.

Earlier, I spoke about the social construction of race and how these constructions can lead to lower health outcomes for Black people. Unconscious or implicit bias can harm the health of Black people and research provides examples of how this

occurs across health practitioners (Grey, 2013; Kapur, 2015). Gatekeepers who control the market employ implicit bias through their membership of a habitus that influences their decision-making. This can result in limited access to the health market which influences policies and practices. For example, Hoffman's (2016) study provided evidence of how these implicit biases born out of biological racial stereotypes of Black women left them without adequate pain relief, as they were viewed as having a higher and more tolerable pain threshold than the wider population.

1.6.9 Health Capital and Cost Containment

Health care is viewed as a foundational commodity, which can be bought like other commodities if individuals have access to the means of capital. However, the demand for health is unlike most other goods because in order to produce "heath capital", individuals are expected to invest time and resources in health such as eating the right foods and undertaking exercise. Grossman (1972) coins the term "Health Capital", to refer to one component of human capital. He theorises that individuals invest in the commodity of health not directly for the benefit of health per se, but in order to gain a greater stock that will determine the amount of time they can spend making money and producing other commodities. Grossman (1972) concludes that once the equal benefit of additional health capital equals the 'opportunity cost' of its production, the individual will then rank alternative combinations of other goods and services purchased in the market. So, for example, because individuals cannot have all the goods and services they want, they need to select opportunities that offer a better value than the choice given up. This can be illustrated using higher education. The choice to invest in higher education as opposed to working once compulsory education is completed is selected with the belief that higher education will maximise their economic utility. With reference to health, this neoclassical approach assumes that individuals make rational choices about how to maximise their "utility" or the amount of happiness produced from engaging in or adopting "good" health behaviours based upon the relative costs of health capital. This investment in commodities such as exercise and health care ultimately enables individuals to replenish their health stock.

Wilkinson and Pickett (2020) posit that the decision to participate in health-improving behaviours is an individual decision based on the expected utilities

gained. However, the Grossman model (1972) makes no allowances for socially structured barriers that consumers may face in society when attempting to improve their health capital. Individuals may engage in unhealthy and damaging behaviours such as unhealthy eating that ultimately increase the demand for health care, due to the limitations of their socio-economic position.

Good health is important for individual wellbeing and health care is one way to improve the incidence and impact of ill health and disease (WHO, 2000). Nonetheless, the lack of appropriate access to good quality health care can result in disparities in health and reduce the ability of individuals to compete and function in the marketplace. This can therefore define the quality of the lives of individuals and health can become like lottery (Graley, 2011).

The market reforms to contain costs in health have seen trends in the rise of gatekeeping roles, which have been charged with decision-making that manage commodities that are market units of intangible cultural values. The hidden processes here consist of how the gatekeeper can use their social power in the market (i.e. their role in Marshall's (1919) 'social credit') to influence cultural judgements in the allocation and management of health commodities. Gatekeeping in health care is a way of controlling expenditure (Sripa, 2019). In economics, one of the principal features of the approach is focused upon efficiency in relation to how it maximises the most benefit from the available resources. Efficiency is measured by comparing outputs to include the quality of care and volume of care given and inputs, in other words, resources used (Moreno-Serra, 2014).

Cost containment as a way of financial control has been used in a number of health care reforms (Propper, 2012), which have in some cases led to trade-offs being made to eliminate unwanted resources at the expense of quality (Bevan, 2010). In the health care system in the UK, there are a number of ways in which gatekeeping is used to manage resources such as GP gatekeeping which limits consumer access to secondary and specialist acute care. Other gatekeeping roles to manage resources are grounded in econometric measures that define quality based upon 'desirable' health states. Under current European Union Charter of Fundamental Human Rights (2009) article 35 states that "Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices." If health care is a human right it belongs (as property) to the individual, if it is a commodity, it belongs (as

property) to the market. The importance of commodification[16] is two-fold 1). In terms of disputing property rights, (North, 1990) 2). In terms of turning intangibles into tradable objects (Zelizer, 1994). In this sense, health care can be characterised as a commodity rather than a human right, (Clarke, 2010) as illustrated through the QALY because there is supply and demand and the QALY determines supply of (Quality Adjusted) health care.

1.6.10 Matrix of Domination and Coloniality

Current NICE guidelines are based on a utilitarian approach, advocated by John Stewart Mill and Jeremy Bentham in the 19th century (Mill, 1863; Bentham (2017[1823]). The QALY, as a health economic evaluation tool in decision-making and the allocation of scarce resources, in effect, marketises emotional attitudes that are intangible and in turn gives attitudes towards health care a market value. For example, the evidence points to high rates of illness from CVD related conditions and at younger ages among the Black population in the UK. Yet, despite the evidence that CVD disproportionately affects Black people, there is no targeted national programme to address this disparity. However, within welfare, extra welfare and capability, beyond 'tangible' money, 'intangible' intersectional issues around age, race, ethnicity, culture and gender, are not taken into account because they are not viewed as having financial costs neither human nor social (however, their neglect actually incurs a "racial tax" as discussed earlier). This shows that if health care is characterised as a commodity and not a human right it can lead to wider social disparities due to the resource allocation frameworks, I described earlier.

Furthermore, decision-making regarding quality and value of one's life has been put under scrutiny by several ethical and moral judgements about "just" and who decides what "just" is. Anyone who can decide "just" has the power. From my point of view, whilst on one-hand QALYs appear to be very scientific (meaning neutral/objective, see chapter 3 about the Western preoccupation with objectivity) in terms of the proxies used for calculations and decisions made, on the other hand, many value judgements about for example race and gender can impact on the decision-making in a hidden unacknowledged way (i.e. "coloniality of

[16] The concept of commodification was originally defined by Marxist political theory as an economic value that can be assigned to something that was originally not viewed as an object that could be bought and sold for monetary value (Marx, 1859).

gender"[17]). There will be clinical assumptions driving QALY calculations and I briefly touch on the cultural roots of these clinical assumptions later in the chapter.

1.6.11 Hidden Factors and "Coloniality of Power"

I will now outline some of the hidden influences of these market value judgements unpacking them more fully using critical race frameworks, mentioned earlier. If individuals need resources allocated to them in order to produce health capital, in other words "costs" ensuring the smooth running of the market for them, what does this mean for ethnic minority groups who are more generally disadvantaged due to their lack of wealth, property, income, job opportunities, progression (Lammy, 2017)?

Based on the QALY, model, does it mean that a higher income implies higher amounts of healthy time (lifestyle choices) and thus a greater demand for health care but those with lower incomes with lower amounts of healthy time have less demand for health care? Higher incomes lead to healthier lifestyles, which lead to greater demand in health care from those who can afford healthier lifestyles. This means that they have a better idea of what's on offer. This model can manifest itself in poor health outcomes for Black people for example, where they have less time to take part in physical activity due to low pay and working in several jobs. I will discuss this important point in my findings chapter.

In 'QALYfying the value of life', Harris (1987) argues that it is unjust discrimination to allocate scarce medical resources to the patients that they determine would benefit most from them in terms of QALYs. Harris (1987) also objects to the QALY because he believes that it adopts a bias towards the allocation of resources to some sections of society at the expense of others. One of the most important aspects to be considered in health economics is; who places value on what? Here, I mean that someone (a body of people, a gatekeeper) has made these value judgements about what are legitimate costs in the whole process of health care provision, including what services or products can be transacted in the health market. My question is focused on who and why and in what cultural context because health economics is rooted in setting priorities, guiding and designing national health care policy reforms.

[17] Coloniality of gender is conceptualised by Maria Lugones (2008) as gender-inflected system to enable colonialism.

From a liberal perspective, Harris (1987) argues that the QALY should use both material and intangible goods if they are to achieve a minimum standard of wellbeing. He argues that 'quality of life', in respect of the current QALY calculations, excludes some individuals, (i.e. those with less social and health capitals) who are essentially discriminated against in the workings out of the QALYs because their lives are perceived to be below the desirable level of well-being.

Racism and its coloniality is a direct legacy of colonialism and can be found in institutional racism as a UK concept that was first introduced and defined over 20 years ago in the Macpherson report (1999). This report recognised that structures and systems that block access to the market (in the context of his report, The Metropolitan Police) can produce different life chances for Black people. Covert racism is seen as normal because it is so engrained and embedded not only in the minds of people, but in the very fabric of society and its institutions. Implicit racial bias as discussed earlier assists in helping to understand the mechanisms of coloniality whereby institutional racism and stereotypes are perpetuated.

In the UK, 'race' is mediated and managed through our institutions and addressed by the state through policies and legislation. In the United States (US) because it has a smaller state in terms of government, the emphasis is directed at the citizen being self- sufficient and doing things for themselves. In the US, activists such as W.E.B. Dubois & Booker T. Washington stated that ant-racism has historically been at grass roots level in terms of what could be done as a community for uplift (Moore, 2003), not being led by the institutions, as in the UK. Later, community uplift was gained through the civil rights movement but in order to get to civil rights there was almost a century of grassroots community action that led to it in the US. The root of the problem in both material and ideological terms is that in the UK, health is managed and administered by the state, through a national welfare institution (i.e. the NHS) and that state institution has historically been covertly influenced by race. Therefore, there are similarities between the US and the UK systems because like in the UK, US systems are also racialised because most African American do not have the Obama Care Act that President Trump has tried to dismantle.

Groups can shape our social identities and how we want to be seen, however, whether as a group we are viewed positively or negatively is reliant upon the opinions of those who hold the balance of power. In terms of the "coloniality of

power", one of its hallmarks is its ability to homogenise the 'other' and that is how stereotypes and market disparities are created. Yosso (2005) argues that if the stereotypes permeate the culture of an institution, the recipients of the service or institution, are then stereotyped and treated in a certain way which can then produce inequality whether it is in health, education, legal, immigration, criminal and justice system.

The Black church is an important institution because it is the only Black institution that can counter the effects of market isolation of its Black subjects. To this effect, the Black church acts to counterbalance the isolating effects of the market. The Black church is about trying make market access available to its members, so it in itself becomes a gatekeeper to the market. The church can be viewed as political, as it can be seen to be building social capital (Saegert, 2001). However, Black-led churches can also play a pivotal role and be viewed as partners in that they could be a dual gatekeeper for the Black communities and one for the health market. Black-led churches in the UK in comparison to White majority churches do not influence policy formation and have not received government support as have the White-led churches. The racist structures have prevented the Black church from being influential in policy and practice across institutions in the UK and the recent Black Lives Matter movement has witnessed a flurry of apologies for the failure of the White-led Anglican Church to respond (Hope, 2020).

Race isn't taken seriously enough as a Non-Goods Characteristic (non-marketable/tangible commodities) within extra welfarism. If race as a Non-Goods Characteristic is not being factored into decisions about allocation of resources, then the individual's agency denies them full access to the health market. QALYs are colour blind and standardise individuals which can lead to individuals being disempowered.

QALY illustrates this as they are not based on modes of different of ethnicities but based upon the white majority an average of a white majority Several examples highlight how the Black the health seeker is locked out of the market in terms of knowledge (education capital) and knowledge of choices for healthier health states (e.g. demanding to be screened and treated earlier, remember, these are search and measuring costs from Coase and North's (1988; 1990) market-as-social-institution model). For example, NICE decisions that fail to meet the QALYs cost-

effectiveness threshold[18] include a new drug called 'abiraterone' to treat prostate cancer that has not been be approved, despite evidence of an increase in the health and life expectancy of individuals with prostate cancer. There is historical evidence to indicate that Black men have a higher risk of prostate cancer compared to White people and other ethnic groups (Odedina, 2009). Several pieces of literature support this and provide evidence that globally, Caribbean and African men are three times more likely to be diagnosed with aggressive prostate cancer than White men in the UK and contract it at least five years earlier (Rebbeck, 2013; McGinley, 2016). So, it would appear that Caribbean and African men who need abiraterone the most, are being deprived of an increase of health and life expectancy, seemingly for the hidden reasons or attitudes (i.e. 'QALYfying the value of [their] lives to be below the desirable level of well-being), that have already been illuminated in this chapter.

1.7. Summary

For me, it was important in this thesis to examine attitudes, stereotypes and structural discrimination (i.e. coloniality and the matrix of domination) surrounding those areas of health that appear to de-prioritise certain health conditions for people of Caribbean and African descent. This links to my personal experiences shared at the beginning of this thesis which state how I observed the de-prioritisation of the health states of my family's friends and how that led to their early morbidity and mortality. Racial constructs have and continue to disadvantaged Black people and this has influenced access to the health market. Given the health disparities identified in this chapter, how could additional efforts be focused towards people of Caribbean and African descent without taking away from those also requiring use of those finite health resources? This thesis provides an insight into the lived experiences of the Black people living in Greater Manchester and the factors that influence their health. These findings may then be used to make recommendations for further work in the area of health disparities for the Black communities.

[18] QALY equation if a product is more expensive than general treatment, it will not be approved, even if it is preventative)

Chapter 2

LITERATURE REVIEW

2.1 Introduction to the Chapter

In chapter 1, I shaped the focus of this thesis by providing my personal reasons for undertaking the study and presented the theoretical framework that underpins the thesis. The chapter placed the conceptual framework and theory as central to the underlying factors that influence the health experience of people from the Caribbean and African communities. In this chapter, I explore what the literature says in general about the health disparities in Caribbean and African communities within the broader context of decision-making, health, socio-cultural factors. In doing this, the chapter assesses the extent to which the literature identifies the factors that impact upon the health experience of Caribbean and African people and the context in which the issues have been concentrated.

Firstly, I will provide an outline of the process I went through to review the literature and how this process led to the themes generated from the literature. From there, I offer a review of the literature that relate to the overall themes I found, which are significant to the theoretical framework and include: biological and genetic factors, culture, faith and socio and economic factors and racism and discrimination. These factors recognise that the health experience is shaped by a number of components that influence how individuals respond or their issues intersect, as discussed in chapter 1. This chapter will conclude with a summary of what was found and the gaps in the literature.

2.2 A Narrative of the Process to find the Literature

My research questions emerged from my personal experience which pushed me to formally explore and scope the literature in more depth. The literature helped me to clarify my research questions due to the gaps that were found to explain health disparities within the Black Caribbean and African community. The starting point for finding the literature relating to my aims, objectives and research questions for this study resulted in the quest to truly scope out and familiarise myself with key studies according to a clearly defined search strategy. The

standard approach using inclusion and exclusion criteria was adopted prior to the primary research being undertaken and is advocated by Heyvaert (2017). This section will provide a narrative of how I found the literature to inform this study.

2.2.1 Search terms

I undertook an extensive search of the literature using a combination of databases yielding data to ensure a sufficiently comprehensive and methodical approach to obtaining peer reviewed sources of reference. I decided not to limit my search strategy to peer reviewed research as this has a number of drawbacks. As peer reviewed articles are judged by expert views, the opinions and views may act as barriers to unconventional ideas and perspectives or may limit findings to experts in the field, (Phillips, 2011). In addition to this, often it is the case that established authors' scholarly articles are accepted and judged on reputation (Lee, 2013). Broadening my search would allow an exploration of some of the background and current thinking in the field that may not be published but used to inform areas of my own research.

This amalgamation consisted of electronic databases; Internet searches using Google Scholar, university library catalogue, searching key terms (see table 1 below) by hand and utilising key organisations as contacts for data references. I primarily focused on literature from the 1950s Windrush generation when most Caribbean and African populations began to settle in the UK and to other countries outside the Caribbean and Africa due to economic migration (Peach, 1996). The work opportunities were largely concentrated in areas requiring unskilled labour and some skilled areas in the public sectors such as in health and transport to rebuild Britain after the World War 2, (Peach, 1996). Although the literature is not restricted to first-generation migrants, inclusion of research studies from this period would capture the health of Caribbean and African people from that era as an important area of baselining evidence. This period was also around the time of the creation of the World Health Organisation (WHO) (1946) movement consisting of United Nations (2020) member states that focused on achieving the highest possible status in health on a global scale.

Three search strategies were adopted.

Search Strategy 1	Database	Ovid Interface
Electronic Library	AMED, ASSIA, CINAHL,) COCHRANE – systematic lit reviews, INTERNURSE – advanced search MEDLINE, EBCSO host - Combined use of CINAHL and MEDLINE Evidence for health. *Science direct – full text database advanced search, nursing and health SCOPOS Scholarly Peer reviewed	African Caribbean and variants - race racial* or ethnic* african* or Black * or non White* or multicultur* or Ethnic or afro-Caribbean, Black, Afro-American, Afro-Caribbean, African American, African Caribbean, African diaspora Health disparities, health inequalities, health equity, prevention, health outcomes, health conditions Cardiovascular and variants – hypertension OR Blood pressure OR cholesterol OR stroke OR Mortality OR Comorbidities Culture OR faith, OR church OR religion OR beliefs identity
Search Strategy 2	Grey literature	'Google' search, resulting in the identification of sources of reference from publications cross sector organisations, campaigns and policy documents, PhDs
Search Strategy 3	Snowball Technique (Ridley (2008)	Secondary Sourced references.

Table 1 – Search terms used

The literature search strategy used MESH and Boolean operator terms OR/AND in conjunction with key words using the three search strategies identified above.

As the key focus of my research pertains to the Caribbean and African communities, a number of search terms and combinations were used to try and encapsulate as many groupings as possible. It is recognised as discussed in

chapter 1 that Black people do not constitute a single, homogenous group and there are major ethnic differences and diversity across and within Caribbean and African groups (Agyemang, 2005). Many of these differences influence the wider determinants of health (Marmot, 2010) such as lifestyle, diet, culture, religious beliefs and practices will ultimately influence life experiences and hence impact on the links between and within groups to realise disparities of the health experience (Nazroo, 2003; Bambra, 2010). As a result, it was important to capture the range of ethnic groupings relating to the Caribbean and African population during the search.

To ensure that not only UK sources were included surrounding health outcomes, but terms were also widened to take account of different perspectives of the approach to public health including a number of defining concepts such as health disparities, which is often the expressed term used in US literature. I use health disparities and health inequalities interchangeably in this thesis

As I gathered the literature, I devised a matrix and recorded the following data.

• Author, year of publication and country of origin
• Defining terms
• Rationale/purpose and location for the study
• Defining terms
• Study design
• Participants including demographic characteristics
• Number of participants
• Outcomes and recommendations
• Conclusions

Table 2: Matrix template of literature

I searched the literature from 1977 to 2020. The reason for this was because the preliminary review of the literature identified that the health disparities policies predominantly occurred in the UK literature during this time frame. The best tool I had to critically appraise assess and judge the data was by using a selection of peer reviewed literature from high impact journals. This critical appraisal of peer reviewed articles enabled me to make informed decisions about the quality of the research evidence by identifying the strengths and weaknesses within those

papers. These were used as my primary sources of data, corrobated by secondary sources of grey literature. Having identified this literature, I began a process of exploring the literature using flipchart paper. I used a checklist to help signpost me the key areas to look for while reading each paper with strict attention being paid to my inclusion and exclusion criteria. As I started to review the literature identified within the matrix, it became apparent that there were several recurring findings in the studies, which were grouped together as they formed themes. The issues identified were health, society, culture, and ethnicity related issues. The data collected also led me back to the literature as I synthesised those findings and began a broader search across the US literature.

My first search of MEDLINE identified over 1400 potentially articles, books and reports but as I started to read the titles and abstracts it was clear that many of the papers were significantly focussed on broader/wider ethnic minority communities that were not defined as Caribbean or African. In order to reduce the number of papers found I looked at those from high impact journals and these helped me to identify key authors relevant to my research questions. I had to be very strict and ensure that I applied my inclusion and exclusion criteria when I was critically evaluating the papers for this study. This provided an interesting contrast to databases such as CINAHL and ASSIA which each identified just over 23 articles on health disparities/inequalities in the Black community however not all in the UK. The purpose of this literature review was to gather material that could inform, but not lead, my study.
Once I collected the data I went back and revisited the literature review. This meant that I went through an iterative process during synthesis of my findings to identify new literature

2.3 Unequal Distribution of Poor Health in the Black communities

In the most recent 2011 England and Wales census, the data presented highlights an increase in ethnic diversity across England and Wales (ONS, 2012). The 2011 Census identifies 86% of the population as belonging to the White category; 7.5% selected the Asian/Asian British category; 3.3% of the population identified themselves as belonging to the Black/African/Black British category (with the largest percentage of this category belonging to the African group) 2.2% categorised themselves as from mixed multiple ethnicities and 1.0% from other ethnic group (ONS, 2012). The demographic picture presented within the England and Wales Census (2011) identifies the notably urban geographical and poorer regions where people from diverse communities are likely to be more widespread;

this includes 55% of the population of London belonging to an ethnic minority group.

Health is often understood from a narrow biomedical perspective with a focus on the absence of disease (Smith, 2018), however, a holistic and more harmonious dimension to health recognises the state of mind, social, and physical wellbeing (WHO, 1946). This conceptual and broader scope of health allows consideration of the conditions in which people live and how this enables them to maximise their full potential (Seedhouse, 1986). Health and illness are socially and economically produced and experienced by individuals in different ways. Throughout the thesis, I adopt health disparities (and sometimes inequalities) as the term which describes the social and economic differences reflected by the social circumstances to which individuals are born into, develop into old age. These are defined as the social determinants of health (Marmot & Wilkinson, 2006). However, even when socio-economic factors are taken into account, Evandrou (2016) found that Black and South Asian people over 60 years old reported worse experiences of self-rated health.

There are a wide range of poor health conditions that the Caribbean and African population is at risk of developing, therefore, several conditions could have been elected for exploration for my thesis. These include certain cancers such as bowel and prostate cancer, mental health conditions, HIV, lupus and fibromyalgia and so on. For me in this context, CVD is emblematic of a health inequality because from this, other conclusions may be drawn about the hidden factors that might influence the disproportionate burden of poor health conditions that affect people of Caribbean and African descent. It is worth providing some further literature on CVD within the Caribbean and African communities because of the initial focus on this for phase 1 of the data collection. By choosing CVD as a hook for conversations in phase 1 of this study, I present the existing literature which alludes to the prevalence of its contributory factors such as lifestyle, social factors, cultural beliefs that are belied by the hidden factors of market relations.

2.3.1 Cardiovascular Disease within Black populations

The World Health Organization (2000) identified Cardiovascular Disease (CVD) as a ‘global epidemic’ and governments across the western world have focused upon interventions to reduce the prevalence of the disease. However, within the general population in the UK and globally, CVD accounts for over a third of all

disabilities and death (Agyemang, 2007, 2012) and it is said to account for 21% of the overall annual NHS expenditure (Luengo-Fernández, 2006).

CVD is an umbrella term to describe a spectrum of diseases that affect the heart and circulatory system. These diseases are largely caused by a blockage that prevents blood from circulating to the heart or brain due to either a build-up of fat deposited in the blood vessel wall or because of bleeding in the blood vessel or blood clots (Marieb, 2012). A few disorders associated with CVD-related disease include coronary heart disease, stroke, and peripheral vascular disease and consist of multifactorial aetiologies. However, CVD is not evenly spread within the population and there is a marked enhanced susceptibility to the disease relatively early on in the lifespan for people from ethnic minority groups (Agyemang, 2009; Astin, 2010; Tillin, 2012; Gill, 2017)

In the UK and internationally, there exists a strong body of evidence to support the increased prevalence of CVD within the African and Caribbean population (Agyemang, 2009; Tillin, 2012; Astin, 2010; Dungu, 2016) resulting in health disparities which can be described as avoidable and health inequities which are unavoidable due to differences from birth (Whitehead, 1995). Because African and Caribbean people are at greater risk of hypertension; a risk factor for Cardio-vascular Attack (CVA) and End Stage Kidney Disease, (Raleigh, 1997) they are more likely to suffer higher rates of mortality than Caucasian people. Compared to the Caucasian population, statistics suggest that people of African and Caribbean heritage have twice the risk and mortality from CVD related conditions which can be explained by a number of determining factors.

High rates of cardiovascular disease (CVD), obesity and diabetes among Black people have played a role in the disproportionate co-morbidities and mortality associated with COVID-19 (Barron, 2020; Fenton, 2020; Platt, 2020). A number of studies have highlighted reasons why Black people have been adversely impacted from COVID-19. Barron's cross-sectional study identified a mortality risk that was 1·7 times higher for Black people (Barron, 2020). Other studies point to socio-economic factors of poor housing and environmental exposure in densely populated areas (Williamson, 2020) and employment in health and social roles.

By and large, much of the UK evidence focuses on the cause of CVD prevalence from a biological/medical socio-economic perspective (Cappuccio, 2007; Chaturvedi, 2003; Danaei, 2014; Kaufman, 2015). Some point to migratory lifestyle variations as reasons for the predisposition of Black people to CVD related

conditions (Brown, 2007). A genomic study undertaken confirms a limited number of replicated associations that provide a genetic reason for high rates of CVD in Black people compared to White people (Loannidis, 2004). There are genetic differences within racial groups and therefore applying genetics to an entire socially constructed racial group cannot be generalised. Genetic reasons have therefore not provided the evidence to explain the disproportionate burden of this disease placed upon racialised groups (Kaufman et al., 2015).

Cappuccio (2007) reports on the inequalities that exist for people from the Caribbean and African diaspora and the development of hypertension (high blood pressure). This is a major contributory factor in the development of strokes and heart disease (Mackenbach, 2011) and there are several social and economic factors that indicate how status (such as education, income, or occupation) can manifest itself and contribute to poor health outcomes.

In summary it is clear to see that the roots of these differences in the manifestation of CVD presentation, diagnosis, detection and treatment within 'ethnic' groups is of paramount importance in improving health outcomes.

2.3.1.1 Non-modifiable risk factors

Ethnic origin is a non-modifiable risk factor in the prevalence of developing CVD and people of Caribbean and African descent are at increased risk (Agyemang 2012). In the UK, as in other developed nations, the risk of CVD related conditions such as hypertension tends to rise with ethnicity, age and gender (Agyemang, 2012). Ageing is a risk factor for cardiovascular disease, however, for people of Caribbean and African descent, it is well evidenced that the development of factors for CVD commences earlier (Chaturvedi, 2003; Cooper, 2005; Dungu, 2016). Using statistics from the American Heart Association (2014), African Americans developed heart related disease before 50 which is 20 times earlier than that of white people. A similar trend to that is found in the UK where Caribbean and African people are more likely to suffer CVD complications and at younger ages (Tillin, 2012). Given the evidence that the incidence of CVD trends profile for Caribbean and African people appears at younger ages, it could be assumed that public health strategies would target people of Caribbean and African descent for CVD screening before the national target of 40 years of age. However, this does not happen and could be due to a lack of response to health needs.

2.3.3.2 Modifiable Inherited Risks

This section of the chapter focuses upon the literature pertaining to the modifiable inherited risk factors for CVD. Studies that have emerged examined findings to indicate biological and/or genetic determinants as the overriding factor for lack of control of hypertension.

Clearly highlighted within the literature is evidence of a number of modifiable factors and interventions with the potential to reduce CVD risk such as diet, physical activity and stress reduction. For example, Danaei's (2014) study recognised high blood pressure as the leading risk factor for over a third of cardiovascular mortality in the United States. This was closely followed by lifestyle factors such as smoking, lack of exercise, diet, and metabolic risk factors such as obesity and high cholesterol. Brindle (2006) also identifies the risk factors as highlighted above and recognises the preventable modifiable strategies, however he emphasizes that although improving lifestyle and dietary intake can lead to a reduced risk of CVD, the evidence for drug therapy intervention to all over 55 years of age had a greater impact to prevent premature mortality from CVD.

2.3.3.3 Hypertension

Within the UK, hypertension is defined as a persistently increased pressure of blood in the arteries. The blood pressure figure is usually presented with an upper figure, which measures the pressure in blood vessels when the heart beats. The lower figure indicates the arterial pressure within the heart when it is relaxing. A blood pressure above 140/90 normal systolic and diastolic (contraction) thresholds is characterised as a high blood pressure and has been recognised as one of the most significant risk factors for CVD related events (Tillin, 2012). Hypertension is classed as the silent killer and there are no obvious symptoms, so raising awareness regarding blood pressure levels is key to early detection so that action can be taken to treat and manage the condition (Gill, 2017). The literature points to the economic benefits of early detection, treatment and management to avoid expensive interventions such as heart surgery that may result because of late diagnosis. However, one should consider what is meant by early intervention and what this may, in reality, mean for people from Caribbean and African descent who have barriers to accessing health care.

Findings from a number of studies point to early onset of hypertension among people for Caribbean and African descent. Agyemang (2012) undertook a secondary sourced cross-sectional analysis to assess the onset of hypertension for a sample of over 18-year-old people of Caribbean and African (n=1,379) in comparison to White population (N=21,344). The research team also assessed whether the hypertension was in anyway related to the changes in BMI. The study established that the age profile for hypertension for people of Caribbean and African descent occurred at an earlier age and recommended early clinical screening for this population group than the recommended UK age of 40.

Population-based studies have highlighted that prevention of hypertension to decrease morbidity and mortality from CVD events rely heavily upon early diagnosis, appropriate treatment and management of the hypertension (Gill, 2017). Not only is the likelihood of reduced prevalence of morbidity and mortality of benefit, there are also health and economic gains for the individual and society attached to early detection, adequate treatment and appropriate management hypertension in comparison to expensive surgery as a result of delayed diagnosis (Gill, 2017). Ethnicity has been identified as a risk factor for CVD and a number of studies have advanced understandings of the relationship between the incidence of hypertension and CVD events among people from the African diaspora.

In a study from the 1980s and 1990s Chaturvedi (1993) suggests a number of biological factors could explain the correlation between the prevalence of hypertension and subsequent CVD risk within Caribbean and African participants in their study. This cross-sectional study of three ethnic populations including 143 Caribbean and African men and women age 20 - 69 was carried out between 1989 and 1991. The findings indicate a possible CVD risk as a result of left ventricular hypertrophy and smaller decreases of nocturnal or resting blood pressure. This is thought in part, to be due to the higher night time blood pressure with a smaller degree of nocturnal blood pressure dip comparative to other ethnicities. This constant strain on the heart and damage to the walls of the arteries ultimately leads to organ damage; clogging and haemorrhage resulting in CVD events, namely stroke, morbidity and mortality. This study followed up by Tillin (2012) 20 years later where the mean age for participants was 67 years old supported the earlier finding of the highest stroke morbidity and mortality within African Caribbean participants. However, reasons for the existence of these genetic factors were ultimately inconclusive (Tillin, 2012).

Cappuccio's (1997) population-based survey study was designed to assess the management of cardiovascular risk factors across ethnic categories of Whites, African descent and south Asians in South London using a sample of 1578 names from GP registers. Equal numbers of men and women aged between 40-59 were within each ethnic group and sample sizes for each group were around n=500 participants. Each participant was asked to complete a questionnaire and investigators took the individual's height, weight and blood pressure measurements as well as administering a blood and oral glucose test.

Despite age adjustments for hypertension, Cappuccio study (1997) found the highest prevalence of hypertension in both male and female participants of African descent. The African group was divided between African, and Caribbean participants and found standard prevalent ratios of hypertension in people of African descent with similar results in those of South Asian origin. Prevalence among White participants was almost half that of the African group's findings. For diabetes, the ratios were 2.7 in people of African descent and 3.8 in those of South Asian origin.

The literature base provides evidence of the 'ideal' body size and found that most larger size women were within Black communities (Shoneye, 2011). Severe obesity was high overall, but particularly among women of African descent (35% to 45%). Participants of African descent were more likely to have their high blood pressure detected, however their blood pressure was less likely to be adequately managed than other groups in the survey. The study's conclusions recommended that prevention and treatment strategies that reduce obesity should focus on cultural differences and susceptibility to vascular diseases in order to improve health outcomes.

Agyemang (2003) undertook a systematic review of cross-sectional data within 14 UK based studies with the sole purpose of identifying inconsistent findings of a UK study undertaken by Cruickshank in 1980. Prior to that, a further UK study undertaken by Cruickshank (2001) set out to screen for ethnic differences in blood pressure from the three main ethnic groups consisting of White, Asian and African Caribbean groups. The study concluded that, the mean blood pressure of factory workers aged 16-64 years was similar to that of White British. The 78% response rate was balanced between Whites (439 men; 164 women), Black people (173 men; 101 women) and Asians (172 men). Although Cruickshank's (2001) findings confirmed a higher incidence of hypertension than the 1980 study among

Caribbean and African populations, the study took a reductionist view of hypertension. The study did not take account of the type of work undertaken by this group of workers and did not distinguish between race, culture, lifestyle and other factors that can impact upon the determinants of health.

Research findings within the US have focused upon the relationship between discrimination and the health disparities experienced within African American groups across a number of diseases but primarily CVD. Croziers' (2006) study used survey data from a previous women's study. The study that took place in 1997 contained eight questions to measure personally mediated institutional racism and found mixed results that associated levels of discrimination with an increased risk of hypertension in certain subgroups of African-American women. As a result of that, Cozier (2006) recommended that questions should consist of measures that focus upon the stress and coping related to experiences of racism.

2.3.3.4 Cardiovascular Disease and Obesity

Evidence that recognizes obesity related conditions that can impact upon the functioning of the cardiovascular system and other major health organs is now well established (Danaei, 2013). The incidence of CVD related conditions is greater if a person is overweight or has an increased Body Mass Index (BMI) (Staessen, 1988; Burke, 2008; Whitlock, 2009) The impact of excess body weight can cause a build-up of plaque leading to rupturing and blood clots within the arteries ultimately impeding the flow of blood and oxygen around the circulatory system. Although the BMI as a tool is not an evidence base for use within Caribbean and African communities (because of benchmarking to majority White populations), there is some guidance that offers individuals a baseline to determine the normal parameters which can reduce the risk of high blood pressure and other CVD conditions (Tillin, 2015).

Burke (2008) undertook a US population-based study with a sample of 6814 White, Black American, Hispanic and Chinese without cardiovascular disease to assess the association of obesity with CVD risk; their use of medication and subclinical factors. The study found that a large percentage of participants between the ages of 45 – 84 years old from White, African and Hispanic backgrounds were overweight or obese and were found to be hypertensive and diabetic despite their use of anti-hypertensive and anti-diabetic medications. A much smaller proportion of Chinese participants were found to be overweight and

obese, however, the link between a larger body weight and CVD risk factors remained similar as for the other ethnic groups in the survey. Although the research study provided evidence of a clear association between a larger body weight and CVD risk in spite of medication, there remains a debate as to whether overweight or obese individuals constitute an independent risk factor for CVD.

Some causes that may contribute to the outcomes included information regarding the participants' lifestyle or health behaviours, cultural, religious or socioeconomic factors. (Burke, 2008). In addition, the study could have identified whether biological or genetic resistant factors impacted upon the effect of anti-hypertensive or anti-diabetic medication. It would have been useful to know whether participants with symptoms of CVD disease could also have operated differentially across ethnic groups owing to differences in access to care and diagnosis of disease. The study also concentrated on the age group of middle aged to older aged participants that may have skewed the results as CVD risk is largely associated with age.

In a more recent study, Danaei, (2014) conducted a large-scale analysis of data from 97 cohort studies involving 1.8 million Asian and Western Cohorts from around the world. The study was undertaken to assess whether there was a correlation between high BMI and the risk of Coronary heart disease and stroke. They found through their analysis of the cohort studies that there was a clear association between high BMI and the excess risk factors and that reducing three key metabolic factors could cut heart disease by 50%. These metabolic risk factors include: blood pressure, cholesterol and glucose and are independently and together associated with obesity and the incidence of stroke and coronary heart disease (Danaie, 2014). Hypertension was found to account for the biggest risk that was 31% for coronary heart disease and 65% for stroke. Danaie (2013) concluded that controlling the risk factors through improved diagnosis and treatment could prevent some of the destructive consequences of overweight and obesity. Although this study has presented the interventions for controlling BMI and the incidence of coronary heart disease and stroke, it is in no-way a total fix, as it does not consider the other underlying variables that impact upon the reasons for obesity. These studies have highlighted a number of influencing factors that seek to explain the prevalence of CVD for Caribbean and African people, however, they do not go far enough to explain whether there is an association between Caribbean and African people and their health outcomes.

Individuals of Caribbean or African descent are at increased risk of hypertension and have the highest prevalence of severe obesity (Health Survey for England, 2004). Okosun's (2012) study of people from African origin populations identifies a clear gradient increase of hypertension and obesity among people of African origin and CVD related events because of a Westernised lifestyle resulting in an increase in the total levels of sodium in the body especially among women. The study collected data from 7075 individuals aged 40 to 75 years on the increased prevalence of abdominal obesity using measurements of Waist Circumference and waist-to-hip ratio (WHR) and correlated the prevalence of hypertension among African descent populations residing within six nations. The study postulated a clear correlation of abdominal adiposity and increased risk of cardiovascular related events.

Cappuccino (1997) and Chaturvedi, (2003) identify a similar association of the prevalence of obesity with a BMI>30 and hypertension risk among Caribbean and African women residing within the UK. However, Becares (2009) accurately recognises that using BMI and waist circumference (as the accumulation of fat around the waist) tools are largely based upon Caucasian population estimates which may not represent people from other ethnic groups as a result of differences in the composition of bone, lean muscle, visceral adipose tissue and overall different physiological responses to fat distribution. Thus, the universal use of BMI to define obesity and the link between cardiovascular events may be meaningless or inappropriate because of these differences (Rush, 2009). Given that body mass index (BMI) is the only measurement tool available in the UK, obesity (above 27) was found to be more common among individuals of Caribbean and African descent compared with Whites and South Asians. White and individuals of African descent were equally likely to be severely obese with a BMI above 30. Although age was adjusted, hypertension levels were still the highest for individuals of African descent and severe obesity was also highest in this group.

Nightingale (2011) acknowledged the inadequate use of the current definitions of obesity for non-White groups. In response to this, a revised BMI threshold and waist circumference measure was recommended for South Asian populations (Bodicoat, 2014). However, and although the literature recognises that body composition and BMI levels vary among people from Black Caribbean and African groups (Cappuccio, 2008) there are no clear and adequate measures for defining obesity among people of African descent which should also be developed.

The majority of evidence identified through the literature search was quantitative and only a limited number of UK qualitative studies have focused on the African and Caribbean communities to identify the interplay of significant factors that have a bearing on the prevalence of obesity and hence increased risk of CVD. Cozier (2009) conducted a US prospective study of 43,103 Black women between the ages of 21-69. Cozier (2009) (using the same sample from an earlier study in 1995 that focused upon weight gain and racism) suggests that the experiences of racism may contribute to the reason why obesity is prevalent in over half of African American women. The findings from the study (Cozier, 2009) which consisted of eight questions surrounding two variables: everyday racism – 1) how often people act as though you are not intelligent and 2) lifetime racism in response to discriminating treatment within work or job roles. The authors found a significant association between weight gain and the recorded levels of both variables that led to the conclusion that the everyday and lifetime experience of racism may contribute to the high incidence of obesity in African American women. Although quantitative studies can identify prevalence, they are not so good at explaining how social experiences might impact on obesity.

2.3.3.5 Cardiovascular Disease and Diet

There is well-supported evidence that pinpoints the relationship between salt dietary intake and high blood pressure levels, (Aloia, 1997; Khan, 2005, Strazzullo, 2009). Some of the differences in prevalence of hypertension between ethnic groups are thought to be hereditary and a physiological response to salt. Khan (2005) advises that the prevalence of hypertension and CVD risk in the Black population is ordinarily the result of low renin. Renin, which is, produced in the juxta glomerular cells in the kidney is often found to be low and is principally an undiagnosed cause of hypertension (Weinberger, 1996). This form of hypertension, which occurs at younger ages in Black people, results in an impairment of the kidneys' ability to excrete salt (Khan, 2005) that is the active component of sodium.

Cutler (2005) asserts that there is a clear disparity in the life expectancy of Blacks compared to White people that have a genetic basis due to the salt sensitivity. Cutler (2005) discounts explanations of socio-economic factors, stress, slavery, racial discrimination, access to health care as accounting for the main differences in life expectancy. Rather Cutler (2005) takes the view that salt sensitivity accounts

for as much as 78% cases of CVD mortality and that this is a genetic trait that Black people will pass on to their children. However, salt sensitivity is not directly associated with all Black people and the evidence presented determines that those Black peoples' survival of the transatlantic slave passage was due to their ability to retain salt. Therefore, Black people living in Africa who are not descendants of the transatlantic slave trade are not salt sensitive and have the same prevalence for hypertension and CVD related conditions as White people. Within the literature, support for the theory relating to the transatlantic trade movement is inconclusive. This is due to a lack of data from African people who were relocated to other areas of the globe especially those areas where large numbers of African people were dispersed.

Cooper (1997) studied hypertension and sodium intake in seven populations of the West African diaspora. The study focused upon the social, environmental, and genetic characteristics of racial differences in hypertension and found a gradient increase of hypertension, from 16% in West Africa (lower than that for Caucasians in the US) to 26% in the Caribbean and 33% in U.S. This study discovered that cultural, socio-environmental influences with the incidence of obesity and sodium intake had a profound bearing on the development of salt sensitivity. There is also compelling evidence to substantiate the association between salt intake and hypertension which is identified as the most modifiable risk factor for hypertension and stroke (Boehme, 2017).

He (2010) provides evidence of the benefits that sodium restriction can have in the management of mild to moderate hypertension. Public health within the UK report that the optimal levels of salt intake should be 6g per day that is equivalent to 2.4g sodium. However, epidemiological studies suggest the optimal level that our bodies require for good health might be as low as 3g of salt a day equivalent to 1.2g sodium, (Aloia, 1997).

In a western diet, much of the salt consumed derives from processed foods. In Caribbean and African cultural foods, He (2018) reports of higher than the 9g salt intake through use of traditional seasonings and concludes that this has resulted in increased incidence of CVD related events within the Caribbean and African communities. The effects of excreting excess amounts of salt through the kidneys can present consequential problems to the bodies functional system resulting in an increase in blood pressure and the subsequent risk of CVD related conditions (He, 2010). Earland (2010) in their small-scale study examined the traditional

dietary intake of 46 Caribbean and African people residing in the North of England. This study found high levels of salt consumption above the recommended amount in the diet of Caribbean and African people. In addition to this finding, low levels of potassium associated with hypertension was found to be lacking in their diets due to small intake of fruit and vegetables or over cooking of these vegetables, (Earland 2010).

2.4 Cultural Beliefs

The cultural framework that exists for individuals and communities can be a significant factor in the behavioural response to health decisions, behaviours and engagement with services which moves my arguments on from the medical, genetic and biological arguments around health disparities.

Findings from numerous studies identify a clear association of the impact of culture on health outcomes. In the UK, Brown (2007) undertook an exploratory qualitative study to gain an understanding of how health beliefs influenced the management of diabetes in African Caribbean people. The sample consisted of 16 African – Caribbean's with type 2 diabetes over 18 years old who were recruited from self-help groups and GP practices. Thirteen of the participants were born in the Caribbean, the remainder were second generation participants influenced by the cultures of their families. Six males, and ten females were invited to take part in semi-structured in-depth one-to-one interviews in their own homes or in GP surgeries. The interviews were framed within a topic guide which included questions ranging from experience of their own upbringing, knowledge of their diabetes and its cause, to their experiences of the services provided to help them to manage.

Brown (2007) concluded that several factors influenced the way the sample group understood and managed their diabetes. These factors included their own childhood memories and the carefree living in the Caribbean that was less stressful. The participants valued the traditional natural foods and recognised that despite some of the foods being high in sugar, the benefits of the natural surroundings and the hot climate enabled them to be physically more active to burn off the calories. The participants in Brown's study also believed that migration to the UK caused their diabetes due to a cultural shift. This was expressed in relation to the lack of fresh traditional food and hence their consumption of processed foods. They experienced a lack of opportunities to burn off calories due

to the change of environment and in addition were subjected to poor socio-economic situations such as poor housing and racial tension which were all highlighted as contributory factors for stress and hence diabetes. Cultural beliefs on the health behaviours of Caribbean and African participants had a significant impact upon health decisions that extended to non-compliance with treatments and a lack of effective self-management. There was a high level of mistrust in the value and advice of treatment from professionals and many of the participants believed that the chemical nature of medicines did more harm to their diabetes. In addition, participants felt there was a poorer quality of service to Black people and a lack of cultural understanding from services regarding how to meet their cultural dietary needs.

However, Brown's (2007) study does not acknowledge that people from the Caribbean come from a diaspora of islands and that their socio-economic circumstances in the Caribbean and the UK could have an impact upon their health beliefs, experiences and behaviours (Viruell- Fuentes, 2012). A further limitation of the study was the lack of opportunity to gain comparative data across ethnic groups. It would also have been useful here to identify the methodological approach used to underpin and justify the methods used in obtaining the data to gain an understanding of the philosophical stance of the researcher. In the health discipline, papers are often weak or limited in describing the methodological approach they have used to underpin and justify the methods used to obtain the data. This may be due to the restrictions of the journal or the priorities of the findings as opposed to the philosophical nature of the research.

Other studies have highlighted influential factors to include cultural barriers, sexuality and identity to explain non-engagement with health services. The view of African masculine identity was cited as an influencing factor for non-engagement. This was due to the fear that a diagnosis of prostate cancer would question their ability to 'cope' as Black masculine men (Schröder, 2012; Pederson 2012). In addition, the invasiveness nature of digital rectal examinations was also against their cultural masculinity and prevented men from coming forward to undertake screening (Pedersen, 2012). Although there are a number of studies that have highlighted a prevalence in prostate cancer in Black communities, there has been limited targeted efforts to ensure Black men have culturally appropriate and tailored access to information and screening (Pedersen, 2012).

There are different studies which highlight cultural beliefs and practices that can impact attitudes towards health. For example, obesity among professional Nigerian women in Nigeria is reported to be as high as the Body Mass Index of Nigerian women based in the UK. A cross-sectional study and random sample of 1058 men and women from varying socio-economic groups found only 36% of the sample had a normal BMI and those overweight were likely to be women (Akarolo-Anthony, 2014). Some authors such as Enang, (2009) report about obesity and overweight practices and its association with higher socio-economic status in Nigerian adults. A cultural fattening practice in Southern Nigerian women called *nkuho* involves girls between the age of 15-18 going through a fattening ceremony to adulthood where they would be excluded from strenuous work to groom and get ready for womanhood. The grooming practice involved fattening the woman to ensure she was a symbol of wealth for her husband to be.

Cultural and environmental barriers influenced the behaviours of 13 Somalian women in Gardener's (2010) small scale qualitative focus-based study. The findings highlight that although the younger generation of women understood the health benefits of lower body weight, the cultural pressures from older generations that favoured a larger body size led women to adopt the preferences of the older generation. Older Somalian generations viewed larger women to be associated with affluence as in some non-western societies. However, in the western world, lean slender bodies are seen as more desirable which can lead to further stigma and discrimination by those who view larger people as leading socially undesirable lifestyles (Maclean, 2009).

2.4.1 Faith and Health Beliefs

Faith plays a central role in the lives of Caribbean and African communities and it was therefore no surprise to find evidence of the impact that religion had on health management in health decision making. Studies below have shown that regular sociable participation in spiritual activity results in improved overall wellbeing (Tomalin, 2019).

A study on religion and coping identified the role that medical healing versus faith healing had on individuals. In this US study, Taylor and Chatters (2010) undertook a study and found a significant proportion of Black people that engaged in

spirituality, prayer and church activities found it to be a protection factor in stressful events (Taylor & Chatters, 2010)

Research studies largely from within US studies highlight the way in which churches have attended not only to the spiritual needs of their members but also to the health and social care needs of their congregants which include screening to improve health literacy and social activities to address social isolation (Lamb, 2014). In the UK, a qualitative faith-based study examined the impact of improving the mental health knowledge base of 13 lay African Caribbean people. The co-produced pilot study with public sector and community organisations found that lay champions experienced barriers to change with the communities because mental health was considered to be a stigmatising and taboo topic in mental health (Mantovani (2014). Despite the potential to prevent and promote better health such as mental health in the Black communities, existing government strategies such as “No Health without Mental Health do not partner with BMC or Black people to address mental wellbeing. This makes a distinction between research and what happens in practice and as such there is no nationally recognised evidence based culturally informed therapeutic intervention or practices for Black people.

A UK study by Mantovani (2017) explored the association of stigma and mental health seeking behaviour with a total of 26 people from Faith based organisations to include faith leaders, thirteen members and seven regular congregants of African descent. This highlighted the personal impact of stigma which included that of family, society and the stigma felt from within the self. As with other studies CAHN (2020) highlights how religion is used as a coping tool as opposed to using mental health services even though their church leaders lacked understanding of mental health conditions. This study by Mantovani (2017) highlighted the lack of engagement of commissioners with faith leaders to facilitate opportunities for behaviour change. Berwald (2016) also explored the barriers to help-seeking behaviours by interviewing 50 African Caribbean communities about memory loss. The study identified various factors including stigma and lack of trust with the medical profession.

Davis and Randhawa (2006) provide exploratory qualitative evidence from 120 Caribbean and African participants aged between 18 and 30yrs to ascertain the determinants for organ donation. Using a purposive sampling approach, the study established 11 focus groups and interviews across three areas of South London. The most dominant or overriding influence of the participants that resisted

donation was their religion and faith. Davis and Randhawa (2006) also found there was also a lack of trust from the participants in the health professionals, especially in the doctors, to donate due to the fear of racism and discrimination in relation to how their organs would be used.

Similarly, a small sample qualitative study undertaken by Clarke-Swaby (2011) indicated a significant lack of BME individuals signing up as organ donors due to a variety of influential factors. 30% of respondents believed that culture affected their decisions not to become a donor as in the Caribbean it was not in their cultural discourse and against their spiritual beliefs. In addition to this, there was also a lack of awareness about organ donation within the Caribbean and African communities.

2.4.2 Cultural and Racial Stereotypes

Black women remain at 5 times the increased risk of poor maternal outcomes in the UK NHS care system despite research studies that highlight barriers to Black women when using mainstream maternity services. The Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries in the UK (MBRRACE-UK) report has highlighted that over the last few decades Black women are more likely to die from complications to do with their pregnancy. Despite this, there are no targets of focused activity to address this disparity. Knight (2019) suggests that this increased risk may be due to pre-existing health problems and poor care received during the pregnancy and postnatal aftercare of Black women. It is often the case that there are stereotypical reasons given for poor outcomes which include migration, poor language skills, social and economic disadvantage. However, Knight's (2019) report highlighted that of the women that died, 93% of these women spoke English and 63% of them were born in the UK. A survey with 24,319 women identified that Black women received poor care and were less likely to be involved in their care, less likely to be listened to and less likely to be treated with kindness and be spoken to with respect (Henderson, 2013). Other studies have highlighted the stereotypes about the Black female body where the White female body is treated as the accepted ('ideal') norm. Black women are stereotyped as being 'the strong Black woman' physically and psychologically (Collins, 2005; Harrington, 2010) and as such, studies have highlighted narratives of women not being listened to when requesting pain relief during childbirth.

Prostate cancer affects over 47,000 men per year and there is an over-representation of Black men with prostate cancer (Cancer Research UK, 2017). Ethnicity is one of the risk factors for prostate cancer and can be traced back to the transatlantic slave trade (Jones, 2015). Black men are up to 4 times more likely to be diagnosed with prostate cancer yet Black men compared to White men were aware of their risk of developing this form of cancer (Bunker 2002; Anderson, 2016; Enaworu, 2016; Cancer research UK, 2017). Ben-Shlomo (2009) recruited all cases of prostate cancer to a 5-year clinical cohort study in London and Bristol and despite equal access to diagnostic screening services, Black men were found to have a 2-3 times more likely occurrence of prostate cancer. However, the study identified many varying factors such as environmental and genetic (family) reasons being cited for the prevalence (Colloca & Venturino, 2011).

Studies that provide evidence of disparities in health status have revealed consistently poor outcomes across every health level of the health spectrum for people from Caribbean and African populations on a national and international scale (Agyemang 2009; Cappuccino, 2003; Wild 1997). Increasing use of the term “Black and Minority Ethnic”, as is often used by institutions, can be viewed as a barrier to addressing health disparities for particular groups because it is an administrative label that homogenises people. Although I refer to Caribbean and African people, I recognise the term can lead to people making assumptions that anyone that fits into the category has homogenous health needs. It is important to recognise this homogeneity because there are differing relationships between Black people. Fanon (1952:17) recognises this and argues:

> to lump all Black people together deprives them of all individuality of expression. It puts them under the obligation of matching the idea that people have of them. By doing this people would assume that all Blacks agree on certain things although there is a source of conflicts between groups.

This may have material consequences, as it is likely to cloud the disadvantage and real issues required to facilitate engagement and address health. Adopting and using this broad term in such a homogenous way can lead to stereotyping (Bradby 2003) or ‘othering’ (Morrison, 1993) that perceives outsiders as ‘The Other’ as discussed in chapter 1 of this thesis.

Health literacy is defined as the ability to understand, access and use health information to maintain good health. Kickbusch (2001), Rowlands (2015) and Orr (2013) cite this as being lower for people of Caribbean and African descent and that it is a contributing factor to health disparities.

Memon (2016) conducted a UK qualitative study with 26 Black and Asian participants of varying ages, socio economic backgrounds and levels of education. The study sought to understand how they perceived barriers to the access of mental health services and barriers to ways of co-producing more culturally acceptable services. This study highlighted a number of key issues impacting access for this group, which included the lack of awareness, masculinity and the inability to seek help and cultural identity. What was also key in this study was the poor relationships that the participants had with service providers which included lack of cultural sensitivity, language barriers, imbalance of power between the user and the provider and discrimination.

2.5 Racism and Discrimination

Most of the evidence identified through the literature search was quantitative and only a limited number of UK qualitative studies have focused on the Caribbean and African communities to identify the interplay of significant factors that have a bearing on the prevalence of obesity and hence increased risk of CVD.

Ochieng (2013) carried out a qualitative study in the North of England to explore the determinant factors that impacted upon the health of people from Caribbean and African communities. The researchers within the qualitative study undertook in depth interviews with 18 participants in people's own homes to explore the perceptions of Black families to barriers to adopting healthy behavioural lifestyles. The study found that Black families did engage in behaviours such as physical exercise, healthy nutritious diets that was consistent with the preventative advice given by health professionals. However, the families spoke of the wider determinants that impacted upon their health such as racism and discrimination in terms of access to employment and education.

Most of the research relating to racism, discrimination and its impact on health disparities is located within US. Cozier's (2006) study, as mentioned before, measured personally mediated institutional racism and found mixed results that

associated levels of discrimination with an increased risk of hypertension in certain subgroups of African-American women. Cozier (2006) recommended that questions should consist of measures that focus upon the stress and coping related to experiences of racism.

The Tuskegee Experiments that took place in America between 1932 and 1972s (Rusert, 2009) are often used as examples as to why there are so many negative attitudes and mistrust from African Americans in their engagement with health services. The Tuskegee Study of Untreated Syphilis in the Negro Male was a non-consented 40-year experiment using Black men to see what happened to the natural progression of untreated syphilis. The experiment run by Public Health Service officers involved in observing and actively leaving 600 Black men in Alabama with untreated syphilis over their lifetime despite the men actively asking for treatment, which was readily available and considered safe to use. For African Americans, political and social history plays a large role in cultivating mistrust towards engaging with the health system within the US due to the racism and discrimination they have been and continue to be subjected to (Whaley, 1998). As discussed in chapter 1, the racist hierarchies along with Social Darwinian theories of "survival of the fittest" (Darwin, 1868:6) have been used to justify the treatment of Black people. Scientific racism is entrenched in Western society (Barkan, 1992) and this experiment used scientific racism and beliefs about promiscuity leading to high rates of Sexually Transmitted Infections (STIs) to explain low birth weight and miscarriages (Washington, 2006). The view that Black people did not experience pain in the same way as White people also justified their treatment of Black people. Other experiments on Black enslaved women include those by Marion J Sims (1813-1883) known as the 'father of modern gynaecology' who undertook surgical procedures on women after childbirth without available analgesia or consent because enslaved women were deemed as 'property' (Prather, 2018)

There are several studies that highlight the lack of trust of Black people towards health services. As already mentioned in Ben-Shlomo's (2009) study Toms (2016) qualitative study with 16 Black men carried out to ascertain why there was a low uptake of prostate cancer screening found that there was a lack of trust in researchers, the research process and a preference for traditional herbal remedies.

2.5.1 Racial and Socio-Economic Associations in Health

The process of epigenetics is where the expression of genes is altered without changes to the DNA code and can be adapted according to the conditions in which we live. The role of genetic factors and the role they play in health disparities have been debated by scientists, however, race is a poor proxy for genetic background and therefore genetics, cannot account for the racial disparities in health (Braun, 2002; Williams, 2019). There is US evidence that supports the effect of trauma on the unborn child pre-conception that includes events such as colonisation, slavery and the way in which people of the African diaspora have been displaced across different nations (Evans, 2008). Black babies are at increased risk of being of a low weight and 122% risk of dying within the first 28 days of delivery.

A UK study by Kelly (2013) identified the negative intergenerational associations of discrimination and racism on the health of children. Kelly's (2013) cross-sectional study of n=2136 mothers and 5-year old children from ethnic minority groups highlighted the importance of racism as a marker for health disparities in childhood development. A US study that traced n=100 Black women in the last three months of their pregnancies found that Black women regardless of their socioeconomic status were more likely to test positive for higher levels of chronic stress hormones resulting in earlier delivery of their babies (Corwin, 2013).

The experience of Caribbean and African people in the UK has undergone fundamental challenges since the mass migration in the 1950s. There is well-documented evidence of the prevalence of schizophrenia amongst African-Caribbean people, who some assert is linked to genetics or biology (Tsuang (2000). However, it is stated that Caribbean and African people are more often exposed to social disadvantage and racial discrimination that can lead to lower socio-economic status, increased levels of unemployment, social isolation and exclusion and stressful events in Britain (Nazroo, 2007). Kirkbride (2009) assessed the incidence of psychosis in three cities across England as part of the large AESOP (Aetiology and Ethnicity of Schizophrenia and Other Psychoses) study. The three-year study between 2006 and 2009 involved n=500 patients with mental health problems from various ethnic groups compared them with a control group of n=350 healthy subjects. The study identified that it was the poor social and environmental conditions that were causing Black people to develop the symptoms of mental illness. A London-based UK study by Hatch (2016) examined discrimination and mental health among n=1698 African Caribbean migrants, aged

16 years and over. The survey found that migrants were 3 or 4 times more likely to be diagnosed with a common mental health disorder resulting from discrimination. More recently Schofield (2019) asked n=35 Lambeth and Southwark service users for their views on why they believed Black people were more likely to be diagnosed with a psychotic disorder. Participants identified the excess build-up of stressors due to their race, lack of support, internal and external stigma about mental ill-health.

A literature review found other socioeconomic factors did not explain strongly the reasons why there were high rates of Schizophrenia in Black Caribbean's living in the UK. Pinto (2008) found multiple risk factors to be the cause including racism, isolation and exclusion, where people lived and a lack of protective factors to include participation in civic society, parental separation and family breakup.

The Public Health England Report (Fenton, 2020) carried out qualitative interviews with around N=4,000 stakeholders, including Black and Asian minority groups and academics to ascertain the reasons for the high rates of COVID-19 in minority communities. Historical racism, discrimination and implicit bias were found to play a part in the high rates of COVID-19 cases and was deemed to be one of the root cause (Razai, 2021) as it led to higher than average exposure to risk in the workplace. In addition, from the literature highlighted in chapter 2, Black people are at risk from the worst effects of COVID-19 due to their underlying health conditions that existed long before the arrival of COVID-19. There was and remains evidence of a lack of trust of NHS services due to the way Black people have been excluded and treated more harshly and unfairly across public sector systems; this creates a lesser likelihood to engage with services. The report by Public Health England (PHE) says that "Stakeholders pointed to racism and discrimination experienced by communities and more specifically by BAME key workers as a root cause affecting health, and exposure risk and disease progression risk" (Fenton 2020:7)

2.6 Summary

In chapter 1, I provided the social constructs behind race and how that has created hierarchies of privilege for White people. The UK literature base has primarily attributed health disparities to social and economic factors that underpin health differences in outcomes for minority groups (i.e. class-based analysis).

However, the US data provides a picture of racial discrimination as a significant contributing factor to health disparities (i.e. race-based analysis).

Whilst the review of the literature identified several studies that had explored contributing factors (such as the socio economic), which influence health disparities specifically within Caribbean and African communities, few studies in the UK explored how systems historically built on racial constructs manifest themselves in poor health. The UK literature does not provide a strong evidence base for how external factors such as the socio economic, racial, environmental stressors and internal factors (community) combine to create poor health that persists for Black people in the UK, across generations. The literature, therefore, whilst highlighting some of the factors that influence health disparities, confirmed that the focus of my original research questions outlined in chapter 1, was needed in the UK literature base because of its lack of acknowledgement of the impact that the historical social construction of categories of race (that includes the combined factors outlined earlier) has on health. In chapter 6, I point to the missing literature which amplifies the decolonial aspect. This decolonial aspect of my study argues for that invaluable contribution to knowledge

Chapter 3

METHODOLOGY AND METHODS

3.1 Introduction to the Chapter

In the previous chapter, I provided a wealth of literature that confirms the persistence of poor health experienced by people of Caribbean and African descent (Bécares, 2009, Bhopal, 2014, Salway, 2016, Evandrou, 2016) and showed that their health experiences do not exist within a vacuum. Chapter 2 identified a gap that failed to hear the actual voices of Caribbean and African people and what they understood to be the hidden factors sustaining health disparities in their communities.

In this chapter, I present the rationale for the study stating why I adopted the chosen methodological approach to fulfil my aims and to answer the research questions in this study. To explore the experiences in context, I explain why I used a critical ethnographic positioning that was underpinned by Critical Race Theory (CRT), intersectionality and post/decolonial theory to explain my findings in the synthesis chapter. Mignolo (2007) has made it clear about the differences between de-coloniality and decolonisation. Decoloniality comes from coloniality of power that is to identify and trace colonial hierarchies of power that remain since the (formal) end of colonialism. Decolonisation is an attempt at retrieving pre-colonial knowledges. Post/decolonial theory is an approach that has been used to inform and explain my findings in the synthesis chapter because although there were issues around the “coloniality of power, gender and being”, the intention of this study was not to look at decolonising health but decolonialising it (i.e. interrogating the power structures present within it). Postcolonialism is about examining the historical origins of how the health market was set up in terms of race. When we understand that , then it gives the context to why the market acts in the way it does Through the lenses of CRT and Intersectionality, I was able to gather the participants’ stories that uncovered the hidden factors that sustain the health disparities evidenced in the literature.

This chapter follows the methodological approach as outlined by Crotty, (1998) (see diagram 1). The first section begins with the aims, objectives, research questions and the philosophical assumptions that underpin the study (ontology

and epistemology). I then proceed to provide a historical overview of ethnography exploring its origins and the ethical implications that perpetuate the legacy of colonialism and imperialism (methodology). I outline how the core of an ethnographic methodology is to observe and understand the complexity of the cultural lived experience. The final section of this chapter details the practical processes I used to access the field, collect the qualitative data, generate the themes, and analyse the findings of my research (methods and sources)

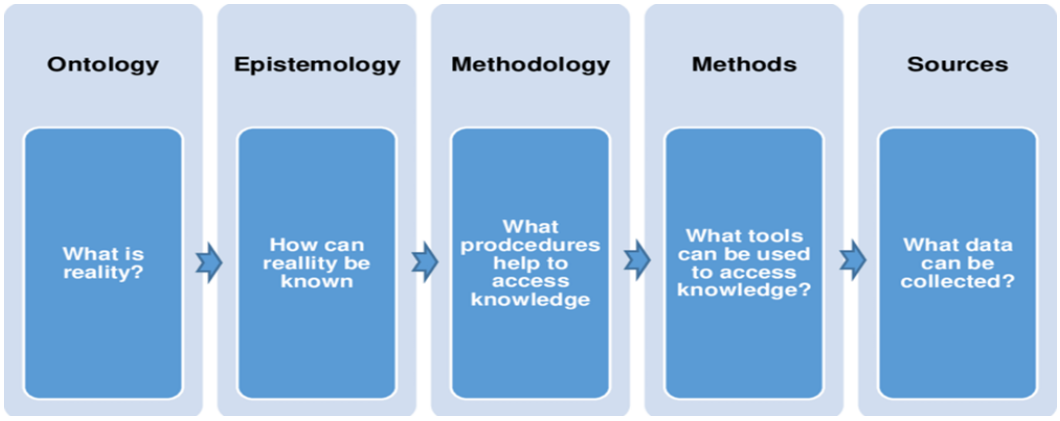

Diagram 1: Methodological Approach (Crotty, 1998)

3.1.1 Aim and Research Questions

My own reality (as discussed later on in the positionality and reflexivity section of this chapter) formulated and shaped the research questions and I began this research with my own autoethnography identifying what led me to undertake this piece of work. The principal aim of this thesis was to identify from the voices of Caribbean and African people, the hidden factors that maintain health disparities in these communities. When I commenced this study, my research focus was looking at the hidden factors impacting the continued prevalence of cardiovascular disease (CVD) within the Caribbean and African communities. As I collected the data from phase 1, I soon realised that although I was using CVD as a hook on which to hang my study, participants wanted to stress the other issues that were of key concern to them. I used CVD as health condition in phase 1 to explore whether strategies aimed at reducing morbidity and mortality were effective for the African and Caribbean communities. The current reminder of the aims and research questions of this study are below.

Aim:

This research is principally concerned with the hidden factors that influence the poor health outcomes of people of Caribbean and African Descent. The aim was therefore to examine what it is like to be a Black person accessing health care in an Urban area in Greater Manchester.

Research Questions:

Research question 1: How is public health information understood, made sense of and experienced in the lives of Caribbean and African people in this study?

Research question 2: What do the voices of Caribbean and African people tell us about their health experience and its influence on health outcomes?

Research question 3: What are the perceived (from a communities' perspective) professional health care behaviours and attitudes that produce poorer experiences for Black People?

3.2 Philosophical Position

From my philosophical position, there is not one reality but many that are constantly being negotiated, debated, and interpreted. There is a world with objects, that can be independently observed, however, once human beings as social actors enter that space, sense-making begins. On that basis, I do not conform to objectivism and the belief that one truth exists. In research, it is important to understand the reality of the participants and consider the approach and procedure used to illicit how we come to know. This section commences with the basis for my philosophical approach to the research.

Ontology is a system of belief that identifies what and how an 'object' is interpreted by the individual, it is about what constitutes a reality or in other words what is (Marsh, 2007). Researchers take a position regarding their opinions of how things really are and how things really work and my ontological positioning focuses on what it means to be a Black British Caribbean woman living in the UK (see chapter 1 for "coloniality of being" (Maldonado-Torres, 2007)). There are types of research questions we generate and that grow out of our ontology which is defined as the

‘theory of being’ (Marsh, 2007). It is an important aspect in research as it is here that researchers set out their position to examine what is known and what exists in the participants reality (Crotty 1998).

Ontology and epistemology work together within the theoretical perspectives of the researcher to shape the research question (Marsh, 2007). In my research study, I asked, what does it mean to be Black and access health care and what is the reality for Black people. I sought to explore health disparities which involve power and questions of race which we acknowledge are socially constructed concepts that are difficult to measure. I use the analogy of wind, we cannot see it, but I know it is there because we can see the effects of it, we feel it blowing. Objective measures to identify and quantify race will not uncover the lived experience and provide the full picture of how it feels to live with the effects of race.

Reality is a product of how we see things evolving and changing which are all dependant upon our own individual experiences. If reality is contextualised and bound it cannot be generalised however but can be moved to other similar contexts. Accepting that ideas of race are socially constructed, we understand race by our interactions with others. Although race is socially constructed, individuals regardless of their race feel the real effects of it and live with the consequences associated with that race (social construct, i.e. “coloniality of being” (Maldonado-Torres, 2007).

Epistemology concerns the theory and nature of knowledge and how this can be acquired (Crotty, 1998). From a knowledge creation perspective, how do I get to know what the reality is for Black people and how can I find out about that? What processes can I use to access that state or being? I wanted to identify the perspectives I could use to make sense of that and understand the nature of the world. Epistemology examines the how we know what we come to know and what counts as knowledge and how we understand that knowledge. The position I hold is that all knowledge is situated and all knowledge has a position in terms of how it is produced, its social relations according to the social identities and where it is located (Haraway, 1988). On that basis, no knowledge or study is neutral because it depends upon the lens that we use to analyse it. For me, I use the lens of CRT and intersectionality because I recognise my own positioning and impact on reading the data I collect. I come to this research knowing that society fundamentally consists of racial hierarchies and that power systematically oppresses people that are not White. Although I occupy a number of roles such as

health professional nurse and a lecturer, my reality is that as a Black woman, I am likely to be looking up from the bottom of that hierarchy because of my racial and gendered identity as defined by colonialism and my location in society.

Guba and Lincoln (1994) identify some key and epistemological questions pertinent in researcher and researched relationships which ask what the nature of the relationship between the individual as the 'knower' or 'would-be knower' is and what can be known (1994:3). It recognises that research is rooted in different levels of privilege where some voices are heard more than others. Having established my ontology and epistemology, this in turn influenced my choice of methodology.

It was important from a knowledge creation perspective that I used the right tools and explored 'how I get to know that' and 'how can I find out about that'. I asked myself what processes I could use to access that state or being. I wanted to identify the tools I could use to make sense of and understand health through their lens as Black people. Centralising the voices of the participants allows for an exploration of the participants' reality. However, it is critically important to recognise the researcher knowledge and influence on the participants because researchers also attach meaning to things, objects, colour and so on (Kuhn 1962).

3.2.1 The Qualitative and Quantitative Paradigm

There are two dominant paradigms, termed positivism and interpretivism. This study prescribes to the interpretivists' view that researchers will create their own perceptions of participants being studied (Pope and Mays 2020). Qualitative research as a 'social inquiry' was popularised by the work of sociologists Denzin & Lincoln (2018) and as a methodology has been subject to a number of critiques that seek to establish trustworthiness (Guba and Lincoln, 1994). Qualitative research inquiry is largely characterised as a paradigm that facilitates use of words, patterns actions or behaviours and pictures, which build a meaningful and holistic rich picture of participants in a natural setting (Silverman, 2017). It is an interpretivist approach that focuses its attention on why, when, who and how people make sense of their lived experiences to generate a theory of people in natural and not laboratory settings (Hammersley, 2018). Interpretivists hold the notion that truth is socially constructed by social actors and can be contested. However, in my study, I adopted an inductive approach as this was a qualitative

study and I was working from the voices of my participants and this iteratively redefined the initial purpose of the study.

My study works within the qualitative research paradigm and recognises that some approaches used to collect data do not explore in depth the lived experiences of the participants or questions may not focus on these actions. This is normal in approaches such as in the quantitative paradigm it is not the intention of this approach to focus on those experiences. The roots of quantitative research lie within a single objective reality or truth and an epistemological positivist perspective. Positivism is a philosophical system that states that there is only one truth and is something that exists independently of the subject and is scientifically validated. It adopts a deductive approach and claims to avoid bias although bias can never be prevented in any research (Marsh, 2007).

The use of participant experiences in my study conflicts with a positivist standpoint because I place importance on the ideology of the subjective experience. This is because I want to understand the lived reality for Black people and their health experience, in other words, their stories and experiences with focus on their accounts which highlight and explain power dynamics and how certain forms of oppression impact upon their lives. Through the theoretical perspectives of CRT and intersectionality, I dismiss the notion of objectivity and measurement and adopt an interpretivist ontology where a single phenomenon may be framed by multiple realities or interpretations.

Researchers take a position regarding their perceptions of how things really are and how things really work. From a critical theorist, perspective, questions are asked which tell us about how reality is shaped by the structures and systems that can oppress some groups and privilege others.

3.3 Ethnography

Ethnography is a late 19th century methodology rooted in the discipline of cultural anthropology and was developed in the period of western colonization (Spradley, 1979, Brewer, 2000; Fetterman, 2010). It is derived from two Greek words meaning ‘Ethnoi’ nations or the ‘others’ and ‘graphein’ meaning writing (Erickson, 2011). It literally means studying people and writing about people in their own communities. Ethnography is built upon the premise that to understand other

people's way of life, researchers must be participant observers which involves living with, eating, working and following the daily routine and patterns of those being studied (Agar, 2006).

Ethnography is not an agreed concept and there are varying definitions and interpretations of it which are linked to the methods used in the research paradigm. For example, Hammersley and Atkinson (2007) describe ethnography as an approach developed largely in contrast to positivistic and deductive approaches whereas some ethnographers take an inductive approach to gathering empirical or primary data within specific situations and interpreting their meaning (Spradley 1979).

My approach to ethnographic research is in line with Hammersley and Atkinson (2007) as I used an inductive process involving lengthy contact with participants and using participant observation and/or through open-ended interviews, which I refer to as focus groups. These interactions were intended to understand people's reality or experiences that contrasts with the view that the social world is an objective, measurable and quantifiable reality as positivists and deductive approaches adopt in their research.

The origins of ethnography come from Bronislaw Malinowski's seminal work in 1914, and belongs to the field of anthropology (Brewer, 2000). Early in the 20th century, Malinowski developed an approach to enable data to be gathered by cultural anthropologists keen to explore indigenous 'exotic' societies, cultures and experiences beyond those of the Western world. Malinowski's diaries spoke of 'othering' as a way of distinguishing between "us" and "them", "me" and "you". Critics have argued that colonial scholarship has and continues to shape interpretations and theories of the non-western world far beyond the post-colonial period (Mignolo 2007). This form of ethnography permits researchers to enter the empirical setting to generate and rely on knowledge from a Eurocentric and ethnocentric perspective which constructs the 'other' as primitive (Harrison, 2008). Shaping interpretations of the 'other' from an ethnocentric perspective where one culture is deemed as more important and superior than the other can be the stick or benchmark by which all other cultures and behaviours are measured. In the area of health, my research recognises the danger of this for individuals and patients as some practices are Eurocentric and have their roots in European

imperialism. This means that Black people that do not fit the Eurocentric perspective (or ways of being; ontology) can be neglected with negative effects on their health outcomes.

What has been evident in the practice of ethnography is the different disciplines that are now using the ethnographic approach to study groups of people and how they interact. The ethnographic approach is located within the naturalistic (interpretive social science) tradition and is increasingly being used to explore the lived experience of people from a wide range of disciplines (Wall, 2015, DePoy, 2016). For example, whilst the roots of ethnography lie in anthropology, contemporary ethnography now adopts an interdisciplinary methodological approach utilised within disciplines such as communication studies, health and medicine, education and sociology. (Denzin, 2018, Gray, 2017). Various forms of health-related ethnography have generated knowledge from ethnographic research. This form of ethnography has produced knowledge to generate health-related interventions, these have been used by researchers who conclude that ethnography can be used in public health (Adler, 1995). However, I argue that critical ethnography is also needed to ensure the health needs of marginalised communities are also embedded into public health policies and practices (Shih, 2018).

Hammersley and Atkinson (2007) recognise that contemporary forms of ethnography have been developed since the original concept that Malinowski developed (Brewer, 2000). However, not all have been embraced because the philosophical anthropological roots of ethnography emphasise the need to generate what Geertz (1973:6) termed as “thick description”. This has been described as the deep immersion of the researcher into the culture of those being studied so that they can gain sufficient understanding of the meanings and behaviours of the group (Geertz, 1973). Pigg (2013) supports the immersion of researchers in the field to produce that ‘thick description’ to avoid a focus on implementing solutions to health problems without understanding the cultural roots causes and nuances of health problems. Pig (2013) argues that ways of knowing about people and the way they live their lives can only be obtained by spending sufficient time engaging with the communities in the field to obtain less powerful voices and better understand the different community’s’ context. Pink and Morgan (2013) contend that this immersion does not require living among the communities but argues that short-term spells or snap shots as I refer to in my study are still

capable of producing valuable ways of knowing about people and their communities. Madden (2017) supports Pink and Morgan's (2013) stance about the nature and essential features of contemporary ethnography, which they agree does not demand that researchers live amongst those being studied. Madden (2017) highlights other ways in which the ethnographers can engage through short term bursts in the field, where they can build theories of people's behaviours and attitudes in their social and cultural context by 'being with' and 'writing about' the lived experiences. Madden (2017) also argues that this can be done using diary and notetaking directly after the interaction with participants as part of their debriefing processes.

Contemporary ethnographers cite immersion in the field for long periods of time as unrealistic and time consuming, (Madden, 2017; Fine, 2017). Although Hammersley and Atkinson (2007) state that ethnography involves lengthy contact with people in the everyday, it is particularly concerned with participation, informal interviews and other ways in which extracts from the field can be analysed and provide a true representation of the cultural group.

Although I had access to my communities through the church and amongst some social circles, I did not spend time living amongst the local communities I was studying but instead conducted snap shots of the lived experience using in-depth focus group interviews and participant observations. This provided me with the 'thick descriptions' that identified through their own voices how the participants understood and engaged in health care.

Ethnography sometimes referred to as traditional ethnography lays the foundation for which all other forms of ethnography is developed. It has evolved to formulate contemporary ethnographies across differing disciplines that includes the critical ethnography adopted in this study.

3.3.1 Critical Ethnography

Critical ethnography has a broader remit than traditional ethnography since it is not expected to be detached and unbiased but designed for change (Madison, 2012). This approach has its theoretical foundations in critical theory (Carspecken, 2005) and was developed in the Chicago school in the 1980's as an

interdisciplinary branch of ethnography (Thomas, 1993). This branch of ethnography is more than just reporting but one form that seeks to capture socio-economic, political, and economic concerns (Shih, 2019). Thomas (1993:2) provides a definition of critical ethnography, which I use in this thesis that argues:

> It is a methodological approach that has its theoretical foundations in critical theory and describes, analyses, and opens up to scrutiny otherwise hidden agendas, power centres, and assumptions that inhibit, repress, and constrain.

By adopting a critical ethnographic approach, hearing the voices of the participants allowed me to examine them and expose the power relationships that socially excludes and marginalises Black people. To this end, I could not remain politically neutral or detached in the face of health disparities facing the Caribbean and African communities.

My critical ethnography shines a light on the health system because it impacts the ability of Black people to access and use health care services. It accepts the foundation of contemporary public health and the well-being of individuals are contextualised by the social, economic, and political world in which they live. Critical ethnographers explore health experiences and examine intersecting identities such as race and gender, as an interconnecting oppressive system (see chapter 1 for Collins' (1990) matrix of domination) that shapes people's experiences of health, illness, and access to health services. Ontology is an important aspect in critical ethnography as it is here that I explore the individuals' views regarding what there is to know of their reality about being Black. We ask questions which tell us about how reality is shaped by the structures and systems that can oppress some groups and privilege others and I seek to make sense of that in relation to how individuals live their lives.

Critical theory in research seeks to uncover and challenge institutional forms of power that privilege some groups or individuals in society and is associated with theorists such as Louis Althusser and Roland Barthes from the Frankfurt School (Thomas, 1993). Those who advocate for the voices of marginalised people to be heard on behalf of the voiceless will support the use of a critical ethnographic methodology which is the 'doing' part of critical theory that we rely on to illuminate social action (Harrison 2008).

Although critical ethnography consists of similar characteristics and methods of data collection to traditional ethnography it shifts the ethnographic question that asks, ‘what is?’ to a critical ethnography which asks, ‘why this?’ and ‘what can be done to change the experience?’ (Denzin, 2018). Critical ethnography is political and used to explore and explain the power relationships and impact of policy and practices on communities of identity (Thomas, 1993). Using various ethnographic methods such as notes from the field, participant observation, and informal conversation, the researcher can explain the systemic structures and cultural aspects of health disparities.

Another key feature that sets critical ethnography apart from other forms of ethnography is the way in which the ethnographer engages in the act of ‘doing’ to address the inequity, injustice and unfairness within marginalised communities. In this sense, critical ethnographers interpret the social setting that is the reality for the participant and shines the lens on the established knowledge that persists to maintain individuals in conditions that promote oppression, unfairness and health inequality (Hammersley, 2018). Those oppressions can create ‘symbolic violence’ which is defined as ‘every power which manages to impose meanings and to impose them as legitimate by concealing the power relations which are the basis of its force’ (Bourdieu 1990: 4). Bourdieu (1990) argues that symbolic classification is central to capital, habitus and class and shows how dominant groups can unconsciously exercise a non-physical symbolic violence which defines their own culture as superior, resulting in class privileges. This symbolic violence produces a legitimate and powerful differential between social groups (Bourdieu 1994). In addition, Galtung (1969) argues that structural violence and institutions can themselves cause harm and keep people marginalised because they create barriers to resources needed for individual development. The social relations that occur in health need to be critically examined in order to gain an understanding of the expressed and everyday ways that health disparities are played out and sustained.

3.4 Ethnography via Positionality, Reflexivity, Knowledge co-analysis, Critical Race Theory and Intersectionality (Intersecting Identities)

The next section of this chapter will highlight four elements of my critical ethnography that discusses the conceptual tools I used to highlight health

disparities in the Caribbean and African communities. I commence this section with positionality and reflexivity because it is the very process of being aware of one's positionality that includes one's insider/outsider status.

3.4.1 Positionality & Insider Outsider Research

The social reality of the participant is jointly constructed by individuals who interact with each other to make sense and meaning of the world through lived experiences. Therefore, researcher perspectives are not only related to philosophical questions about subjectivity and objectivity with respect to those being researched. The colonial element of anthropology as described earlier has driven a kind of research exploitation that is argued to discredit the credibility and nature of research. One of the most important components of critical ethnography is positionality because it requires researchers to recognise and acknowledge that their own power dynamic can influence the whole research process (Cassell, 2016). Critics argue that research cannot be rigorous because of insider positionality as it acknowledges that every element of the research process from the research question to the interpretation will be affected by the individual's own reality (Milner, 2007; Bourke, 2014). Positionality is of concern for qualitative researchers and questions are raised about how multiple identities (race, religion, gender, sexuality, nationality) influence and potentially bias, our view about the world and hence our research (Cassell, 2016).

How we perceive others and how they perceive us will be influenced by those we interact with and how society views their position and status. All these multifaceted phenomena will shift and determine how we engage with others and the choices we make in society. The concept of positionality is directly relevant to the insider/outsider dichotomy, as it raises some important questions about the impact of multiple identities, power and the position of the researcher on the research (LeCompte and Schensul,1999; Jacobson and Mustafa, 2019). It is described as a measure of privilege or disadvantage in research, as there are situations where people attempt to maximise the amount of power they can exercise over other people or groups.

Within positionality is the concept of identity which is not straightforward but is one that is shaped by visible characteristics such as gender, race, class and so

on. Our identities are fluid and situational and these change over time to fit certain circumstances. As our identities are ever changing Naples (2003) advocates that we understand identity as a process that we go through based upon situations and circumstances.

Using a Critical Race Theory (CRT) analytical framework allows a recognition of the role of identities and influence as a researcher and enables a resistance of 'objectivity' in favour of co-constructing knowledge with our participants (Villenas, 1996). Grosfoguel (2007), Dussel (1977) and Mignolo (2000) argue that knowledge is always situated and subject to the networks we live in, so there is no universal truth per se. Mignolo (2002: 57) calls this "geopolitics of knowledge". What makes this dangerous is that this "geopolitics of knowledge" is often hidden and those in positions of power declare their "situatedness" as neutral or the universal starting point. However, Grosfoguel (2007) argues that regardless of where we are located, and how we are oppressed, we can still have the same geopolitical knowledge as our oppressors which is a form of state control.

Segrest (2002) describes the ideology of being born into 'belonging' as a precursor to 'being' which is continually being formed with others. This is what Bourdieu (1984) describes (as discussed in chapter 1) as habitus because we acquire a set of characteristics from different fields or social locations that are learned from where we are positioned with others. These fields are objectively ranked by the system as capitals such as economic, social, educational etc. (Bourdieu 1984) that can be used to gain advantage or privilege in society. From my perspective, this is important as I bring my sense of 'belonging' or habitus into the field and recognise those deemed to hold more valued capitals ultimately holding more power. This links to Grossman's (1972) model of acquiring health capital that I discussed in chapter 1 and fits into Sen's four evaluative categories with a focus on 'agency freedom'. It is here that I argue about the ways in which the gatekeepers through their implicit biases manage the non-good characteristics of the Black communities.

Positionality acknowledges that we each come to the research field from differing cultural, social, political, economic, gendered and racialised contexts and as such, our experiences will shape what we determine to be important from the research question and throughout the research journey. Hall, (1990: 18) states that "There's

no enunciation without positionality. You have to position yourself somewhere to say anything at all".

Merriam (2001) questions the dichotomy between insider, outsider status and what it is that we are meant to be inside or outside of as we as individuals consist of many aspects. Researchers that share an identity with others they are conducting research with are referred to as insiders. The insider status can sometimes offer researchers a certain amount of privilege and access to participants and that is because of the shared identity. This often allows researchers easier access and acceptance by the participants. My identity as a Black woman, academic, researcher, health professional and author of this study, recognises that my outsider-ness/insider-ness status can be complex at the intersections of my Blackness and gender. For example, as a Black academic, I am neither a true outsider of the communities I am researching nor am I a true insider. Despite working in a predominantly female nursing department, I am still a Black female academic working in an institutionally White male-led university establishment. As a Black woman, I am also subject to the same covert racist and gendered views that are found in wider society and expected to perform to fit in (Uchibong, 2016). Collins (1986) describes this as 'the outsider-within', as the views of the Black woman will create different lenses of reality. This awareness of myself as a marginalised critical Black female ethnographer, prevents me from placing myself in the space of a White ethnographer. There is a need to develop a balance between my Blackness as an oppressed being and ethnographer researching Black communities. The questions I keep in mind are; do my Blackness and what it represents, share sufficient common ground with the ethnographic field that I am studying? How do the participants perceive my Blackness and does that impact on their ability to connect with me or the ways in which I connect with them?

These are important concerns because as a Black woman, I am directly under the White male gaze in wider society but also as a Black female nurse academic in a predominantly White male-led institution, especially at senior levels (i.e. White patriarchy). As a Black female ethnographer, I stand in direct opposition to this colonial White male gaze which Fanon (1952) characterises as "mastery" (as cited in Fanon 2008:95). However, from the communities' point of view, do the communities recognise my struggles as a Black female academic and nurse, or

do they associate my perceived position as part of the White patriarchal mastery that I stand against?

My own subjective experiences have unquestionably affected my views of being Black and how I see the world, therefore I reflexively highlight the possible impact my identity, assumptions, biases and my experiences may have had on the study. From a positional perspective, critics argue that race-based research undertaken by researchers of colour result in bias (Pillow, 2003). However, recognising my positionality allows for a narrative account that informs my research rather than invalidates it as bias because of my personal experiences.

Being a Black woman and an academic is important in this context because mainstream (White) scholarly activity in this area is supposedly about neutrality and objectivity. However, there is a challenge to western mainstream White anthropology, which states that you can master the subject through observation. Fanon (1952:2008) states in his book '*Black Skin, White Masks*'

> for the traditional colonial anthropologist to master the cultural tool (subject) is to know everything about it and to diligently detail everything about it. However, when that happens, outsiders have still not understood the group despite all the theories and observations they have collected; they remain outsiders to the communities but think that they have mastered the communities.

This is important from an intersectional perspective because as a Black woman and being a part of the communities, my positionality as an insider is important because I am not trying to practice mastery over the communities, so I am able to observe and interact with the communities in an insider-ly way rather than outsider-ly.

However, in saying this, I initially had to bridge the gap as an academic, as I was perceived as an outsider by some wanting to know all about Caribbean and African lived experiences around their health. I write in my diary about how I broke down those barriers and used my personal history including my personal contacts to remind the communities that I was from their communities.

3.4.2 Critical Race Theory (CRT): Helping to theorise - Reflexivity

Researchers undertaking qualitative research recognise the importance of reflexivity to reduce the researcher effect on the researcher (Berger, 2013). In ethnography, reflexive practice provides the researcher with the ability to critically note down their feelings, emotions and pre-conceptions during and after they have left the field and reflexivity can be the "bridge' between the researcher and the researched (Denzin & Lincoln 2018). According to Popes and Mays (2020) reflexivity is essential in qualitative research as it is this that provides the criteria for assessing the quality of the research. Interpretive research needs to be reflexive and it is through the activity of writing itself that I make sense of the perspectives and experiences of the participants.

In this research, some reflexive elements are extracted from my diary in the findings chapter as this was maintained throughout the research. Adopting a reflexive approach throughout this research has enabled me to discover my 'insider'/'outsider' status, positionalities, differences and the commonalities I have with the different communities being studied.

I initially believed that I was an insider from the communities and that I would immediately be accepted when I went into the research field. This did not happen immediately I needed to be clear about my identity and build relationships with the communities. The importance of an effective relationship for me was key to the success of this ethnographic study. I participated and engaged in discussion so that I could provide a trustworthy picture of the Caribbean and African communities.

Through reflexive practice, I was able to explore 'me' as a Black woman, qualified nurse and health prevention specialist born here in the UK, educated in a British school and university and exposed to socialisation predominantly with those from a White background. This is different to many of the participants in my study from which I was seeking acceptance into their communities. On reflection, I realised that elements of my reality would be underpinned by Eurocentric views that could influence my research (Smith, 2012). However, for me, the lived reality surrounding my Blackness and intersecting elements would have the most impact and inform my ontology, epistemological perspectives and methodological approach. It is within this context that my experiences in and of education, health

and society would influence my research, which I embraced and included as a key element of this study

3.4.3 Knowledge Co-analysis: How I Connected with my Communities

In the academy, knowledge is taken for granted because it has largely been White men that present ethnographic studies. For example, African tribes are presented in a neutral and factual manner because that is what has been observed (Smith, 2012). However, knowledge is not neutral but is situated in the colonial mentality of feeling 'superior' and privilege (see chapter 1 for discussion about "coloniality of power"). Historically, health care evidence has rarely included or acknowledged the intellectual contributions of Black people and it is only recently that race has been acknowledged as a determinant of health (Marmot, 2020). The introduction of CRT for practical research helps to address these challenges because the methods used can help researchers highlight racial biases located in the research process and identify ways to address them (Airhihenbuwa, 2018). On that basis, I worked directly with the different community members in a participatory way and ensured that their voices were heard and documented to provide legitimacy to the research (Young 1990). Without this, the oppressed voice of the participants would be hampered as there are limited opportunities to explore ways to produce knowledge from their experiences.

Freire (2018) argues that there needs to be a counter-hegemonic approach or dismantling of hegemonic control. He argues that this is important for knowledge construction in oppressed communities so that the dominant or more powerful interests and perspectives can be challenged. To reduce that power imbalance between researcher and researched, Neilson (2019) describes how ethnographic approaches can facilitate the involvement of its participants into the collection, analysis and interpretation of data. Aldridge (2014) supports this and highlights that this approach is one way to avoid the imbalance of power between the researcher and of those that may already feel vulnerable, stigmatized, exploited, and marginalized.

It was important throughout this research that the involvement of the communities was not tokenistic and that they were truly empowered to participate. Whilst it is recognised that the researcher needs a degree of power and control to carry out

and direct the research, I placed emphasis upon on negotiating and developing equal autonomous, empowering relationships within the participants' own natural settings.

What this study set out to do was to use the tools that would allow me to uncover truths and the reality of the lived experiences of Black people. In this study, I adopted the view that the "emic" approach where the "insider" researcher can develop theory from the ground up whilst at the same time recognising the value of the literature used upon which this study is based, would be more appropriate rather than the "etic" "outsider top down approach of applying theory to the qualitative data, (Madden, 2017).

3.4.4 Methodology through the Prism of Race

In critical ethnography and through the prism of critical race theory, the voices of the oppressed can be heard. Taking an objective approach would not capture the lived experience of Black people. The earlier discussion articulated how I adopted a critical ethnographic approach to explore the narratives of the participants and uncover the hidden factors influencing the health outcomes. This approach builds on the ethnographic tradition of gathering the perspectives of the researched to challenge the policies and practices that generate the inequitable power relations (Thomas, 1993; Carspecken, 2005), which for me related to health institutions. This approach was important because I needed to apply the critical theories around race and gender to my ethnographical field (Solorzano and Yosso 2002) and identify the liberatory element that could help to bring about a solution to the poor health outcomes of Caribbean and African people.

As discussed in chapter 1, CRT is an analytical framework that provides a tool to pursue social justice and the elimination of racism (Crenshaw 2002). At the root of CRT is the personal narrative that acknowledges race from the start, this is despite some of the critiques that were levelled against CRT during its inception about the subjective nature of the approach. It is doubtful that objectivity as a methodology can accentuate the voices and experiences of people from marginalised racial groups. It is more often the case that in positivist research that the power dynamics are unrecognised, and the voices of marginalised groups are the ones that can

get silenced (Serrant, 2020). CRT examines the ways in which race is manifested in the daily lives of Black people and is about their personal narrative.

CRT in this study is used to interpret the voices that remain unacknowledged invalidated and distorted in social science research (Smith, 2012) so that the voices can be used as a strategy to inform, reveal, and better understand the experiences of Caribbean and African people.

3.4.5 Intersectionality (intersecting and multiple identities)

Chapter 1 provides the theory of intersectionality and recognises that complex forms of inequality and social interactions, (Crenshaw, 1989; Collins, 1990) cannot be untangled in isolation of other intersecting dimensions such as race, gender, disability, faith, class and age. Intersectionality is a theoretical framework for understanding how the different identities are made up of a range of intersecting aspects of human beings. We are racialised (especially as Black but also White) but racialised differently because of other competing identities. These intersecting identities result in the creation of further complex different forms of societal discrimination that Collins' (1990) identifies as a "matrix of domination". In this study, I wanted to capture not only the lived experiences of the participants through the prism of race (i.e. "coloniality of being" (Maldonado-Torres, 2007)), but also to identify how the other intersecting factors might have impacted upon health disparities within the Caribbean and African communities. Intersectionality is an important and relevant aspect within health as Black people are not protected across the health market in relation to its policies and are subject to universalism that does not consider the diversity of the intersecting vulnerabilities that impact upon their health outcomes (Collins, 2000). Throughout this study, I examined my own identity as a Black female researcher and health practitioner, as I am racialised and gendered and subject to discriminatory practices. Therefore, this study acknowledged intersectionality as an important lens to explore participant experiences in health as it recognised the complex intersections across race, ethnicity, gender, faith and culture that the participants voiced, as they navigated access to health in their daily lives.

3.5 Phases of the Study

Ethnographic research was considered the most appropriate method to address the research question as it requires ways of collecting data that will allow an exploration and interaction of the participant in their own real-life environment. (Fetterman, 2010) This section outlines the practical steps involved to address the research question, aims and objectives.

The study consisted of three phases (see diagram 3 below).

Phases	Duration	Methods	Participants
Homework	**8 weeks**	**Fieldwork Diary**	**Communities Gatekeepers Caribbean and African attendees at the community centre**
Phase 1	**4 weeks**	**Focus group interviews Fieldwork Diary**	**Communities Public sector gatekeepers**
Phase 2	**6 weeks**	**Focus group interviews Fieldwork Diary**	**Caribbean and African Communities participants**

Table 3 - Phase 1 and 2 Overviews

3.5.1 My Approach to Critical Ethnographic Data Collection

In my study, I went through a number of stages to undertake the fieldwork that included thoughts about where to conduct the fieldwork for both phases, gaining access to the field, how I conduct the fieldwork and also how I left the field on completion of the data collection. How I addressed these stages are presented later on in this chapter however prior to that I will identify the tools I used to collect the data.

A qualitative approach was chosen to address the research question. This method takes account of the ontological and epistemological positioning I subscribe to because it is concerned with understanding the meaning that people attach to their experiences within their own reality. In this study, I used focus groups to collect the data and my field work diary to gather my reflections, as I interacted with the participants. The phase 1 focus group sessions were interactive and consisted of discussions around public health workshops and questions (see appendix 1a-d).

Ethnography-research generally employs a triangulation of methods in one study to include observation, interviews and documents (Fetterman, 2010). This ethnographic approach provides a flexible choice of methods within the field and provides the researcher with the opportunity to connect with their participants and tell a story of their experiences (Hammersley, 2018).

Participant observation is a research tool rooted in anthropological research and involves gathering detailed accounts from within 'naturally occurring setting' (Spradley, 2016). However, to gather my experiences, I used my fieldwork diary data to annotate my reflections from the engagement I had in the field during the study. Initial observations focused on taking part in activities and getting to know people in the centre (the community venue for the research), this included negotiating some of the rules which were later applied in phases 1 and 2. Although, I come from the Caribbean Jamaican community, it was important for me to orientate myself to the different communities' ways of doing things and to be able to build those relationships prior to the actual data collection sessions. By undergoing this pre-phase, I was also able to test out the objectives and whether they were appropriate in the context I had selected.

During my time in the field, I took snapshots of the lived experiences and provided my reflections in my fieldwork diary. This approach was selected because as well as being a research process, it was also a way to provide a subjective, authentic and interpretive account that produced knowledge within the participants' own reality (Pink, 2008).

Focus groups interviews were best suited to complement my reflections in the field because they share characteristics of ethnographic research with an emphasis on informal conversational open-ended questions that can produce data for analysis. My focus group interviews provided an opportunity for people with similar

characteristics to come together and generate feeling of self-worth, as they all shared how they were feeling about accessing health in their daily lives, in a safe space.

Focus group interviews produce rich in-depth data, however, to generate this, Krueger (2014) suggests six to ten participants as an ideal range in which to recruit participants to focus groups. This is often cited as a disadvantage of focus groups as the sample sizes tend to be small and therefore the results cannot be generalised. However, it is important to generate enough in-depth data and to allow it to be as inclusive as possible for all participants involved (Kitzinger 2006). One of the key benefits of focus group interviews for my study was that they allowed participants to interact with each other and determine the direction of the organised discussion with minimal interference from the researcher. This is where I was able to establish an understanding of the participants' own reality of the issues under discussion and empower individuals to have their voices heard to make a change. This interaction between members of the group is the crucial feature of focus groups because the interaction between participants highlights their views, the language they use to express issues and their values and beliefs about a situation (Kitzinger, 2006). Interaction also enabled participants to ask questions of each other, as well as re-evaluate and reconsider their own understandings of their specific experiences. Focus groups interviews were guided by a framework of questions with inbuilt activities (see appendix 1 a-d phase 1 and appendix 5a phase 2) these resulted in rich and in-depth data. This can only take place if trusting relationships are built between the researcher and the participants.

My fieldwork diary was a useful tool for capturing and reflecting on my experiences in the field as I interacted with the participants. My diary consisted of my participant-observations, as I positioned myself within the field as a participant taking part in group conversations and activities such as eating and drinking after the planned focus group sessions. This is a form of data collection method common in qualitative research paradigms and rooted in ethnography research and gathers detailed purposeful and systematic descriptions and representations of participants in a 'naturally occurring setting'. It has spread to other areas of research studies in social sciences including communication. Malinowski use of participant observation helped him to take an active role in the lives of those being studied and develop close relationships. Across all phases of my study I was able

to actively observe and participate in activities in the field whilst taking mental notes of certain key observations so that I could write them once I left the field

3.5.2 Homework – Pre- Phase Building relationships in the Field

This process of building relationships and making connections to the communities commenced using my own initial network of relatives and family friends who could assure my integrity and put me in contact with gatekeepers in the communities to help create and build relationships. In my fieldwork diary, I note the apprehension I experienced when I contacted individuals whom I was directed to by family that did not openly embrace what I was doing. The lack of response from the gatekeepers to my request to hear about my study made me question my insider status (see Appendix 12a fieldwork diary).

Until this point, I viewed myself as an insider or as a member of the communities as I had commonalities with the group that I was studying for example, I am of Caribbean and African descent. For me, this meant that I had privilege and therefore more likelihood of gaining access to the target group (Adler, 1995). I questioned my status asking myself whether my credentials as an academic, researcher and health professional rendered me an outsider simply because I was not readily accepted. However, others have argued that there are other factors that frame the individual's identity to include variables such as their culture, their political view, religion, race, gender, educational background, class and socio-economic status and this will determine whether they are viewed as insider or outsiders in the research process (Collins, 1986).

For eight weeks during the homework phase, I visited the activities in the church hall as I did my homework documenting my experiences in my fieldwork diary.
After ethical approval had been gained from the university (see appendix 6), I was able to commence contact with identified individuals to gain access to the 'field'. I refer to these contacts as communities' gatekeepers because they were deemed to be well-networked individuals that had access to large sections of the communities I wanted to engage with for my study. Although I am a member of the community and attend similar activities as the participants did, the field was still a place for gathering data about the participants lived experiences.

I was initially directed to the communities' gatekeepers through family and friends from the local communities because many of these individuals led community organisations. This purposive sampling effect led to individuals signposting me to other communities' gatekeepers within the communities allowing a wider selection of Black people to connect with outside of the immediate local area. For me, the communities' gatekeepers were crucially important mediators (Eide & Allen, 2005; Hammersley and Atkinson, 2007). Gatekeepers are defined as individuals or institutions who have the power to either grant or block access to a research population (Latchem-Hastings 2018). I was quick to realise that although this relationship with the gatekeeper was important, it did not guarantee immediate access to the communities (Shaffir, 1990; Wanat, 2008). Before I could access the communities, I needed to build relationships with the gatekeepers. This pre-phase part of the research which I refer to as homework included eight weeks of establishing relationships to gain access to the communities and recruit participants. It involved spending time with the local Caribbean and African communities in the church hall where lots of social activities took place. During this time, I was able to participate in a number of activities and spend time talking to people. This helped me to form relationships with the local communities in preparation for my data collection. Building meaningful relationships is described in ethnography as one of the most important functions, (Harrison, 2008). Clennon (2014) also highlights the importance of devoting an adequate amount of time to building and relationships in the communities.

One of my earliest realisations was about the power that communities' gatekeepers had to the users of their services. It was apparent that the only way to gain access to potential participants was through the relationship and trust that had been built between myself and the gatekeeper. I soon appreciated that without a consistent effort to build trusting relationships with the gatekeepers the objectives of my research would not have been achieved.

Spending time with the communities' gatekeepers allowed me to develop questions for teasing out the effects on everyday life. I arranged a meeting with two of the communities' gatekeepers and they were able to help me to scope some questions. It was a useful approach to take because they knew their people and what they would be more likely to respond to. It also helped me to build

communities' ownership in from the start. I describe this as knowledge co-production because they helped me to design the questions for the research.

3.6 Phase 1 - The Fieldwork Settings

Following consultation with one of the communities' gatekeepers during the pre-study (homework) phase, the agreed location for the study was at a Community Centre in central Manchester. The slot I was given had been provided to me by a woman whom I will call Janet for the purpose of this study. She used the centre every Thursday morning for activities for older people. This was deemed to be a good location as it already was used by a large section of the Caribbean and African communities and it was considered a space where the communities would feel comfortable and at ease.

3.6.1 The Location

The centre was a large multi-purpose facility where church services would be conducted in the main auditorium and communities' activities would take place in the church hall. The space had separate rooms for private meeting rooms, which became important for me as there were two occasions when community members wanted to talk to me privately. The communities' space also accommodated a large kitchen, which emphasised the importance of food as a social activity. The centre would prepare meals for attendees during lunchtimes and for those that could not attend for physical health or other reasons. They also had a Saturday soup kitchen facility for the communities that I also attended during the pre-phase period of my study. I was keen to engage a cross section of people in my sample so that I could gain a range of lived experiences and hence it was important to undertake the research in a place that people could be accessed from across Greater Manchester including those across urban and suburban areas.

People that attended the centre came from across Greater Manchester and because many of these were older people, they would use the church mini-bus to bring people to community and church activities. The centre is a well-known venue for weddings, funerals and other events used by the communities. Although I had permission from the communities' group to use their slot for the focus group sessions, I awaited approval from the pastoral board that responded positively to

the request. The minister invited me to share this with the congregants and place posters within the church. As we discussed the focus group sessions, the pastor suggested including the provision of culturally appropriate food as this was deemed as a way of saying thanks to the communities for their contribution. It was also an opportunity for the informal conversations to take place following the two-hour directed focus group session.

3.7 Recruiting Researcher Helpers

I recruited former students as research helpers to support me in the field as I collected phase 1 data. The research helpers were all interested in working with the Caribbean and African communities and they were either of Caribbean, African or Caribbean and African descent. The research helpers were either born in the UK or in West Africa, however all had lived in the UK for more than five years. All were within the age range of 38 – 49. I decided to use research helpers to support me during phase 1 of the study because it would be difficult to oversee the focus group sessions as well as facilitate them. At the time of recruiting the students, I did not know how many participants would attend because it was an open forum where people could join in the focus group on the day if they met the sample criteria.

During the recruitment process for research helpers, I shared the purpose of my study and these former students who had experience of collecting data were particularly keen to support me to capture the data. Prior to each the focus group sessions, each of my 6 research helpers were offered guidance and support for their role as research helpers and were prepared with information about the study over a three-week duration. I wanted to ensure that each research helper was provided with enough knowledge and guidance to be able to understand and empathise with any of the issues raised by participants. This involved a pre-meet session that went through the aims of the research session and how they could support. I spent time ensuring that the research helpers had the necessary information to conduct themselves in an ethical manner. I used the participant information sheet as a guide to help to protect the participants information during the data collection process.

During my overview of each session, I provided the participants with an introduction to each of the research helpers stating their role in the focus group sessions because I wanted to create a comfortable atmosphere for the participants so that they could contribute openly. This was supported by the fact that all research helpers were Black.

On average, the focus group discussions lasted approximately two hours and took place in the community setting. Each research helper gave an introduction of themselves to the participants as they took the same table each week. I asked the research helpers to support the focus group sessions and gather the data on flip charts. They would also remind each focus group about the ethical practices of confidentiality and respect for each other's experiences. The research helpers were also responsible for reminding the participants about the recording of their voices and reinforcing issues of confidentiality. They also took the anonymised register (see example in the appendix 3) on each table so that I could identify who said what when it came to the analysis. Their role was to support participants after I introduced the focus group session, its instructions and facilitated the overall session. During the session, I would interact with participants as they discussed the key issues as per the session plan. Each research assistant would feedback the comments from their table (see appendix 10 for flipcharts from helpers' feedback) and I would then summarise the commonalities to wrap up the session.

After each session, the research helpers would provide information about the group that they supported, their notes and their tables' audio recording. During the preparation sessions for the focus groups, research helpers had suggested ways to clarify and check understanding about the aim of the activity, how they could assist, engage participants and encourage discussion in all relevant areas. As each of the research helpers were from the same demographic as the participants, we discussed how they could also influence the research study and I wanted them to be aware of that. During the feedback session, the research helpers spoke about how they felt in supporting the sessions and the impact they felt they had on the participants as they also shared some stories during the sessions. These formed reflections from the research helpers and I include a sample of these in my phase 1 findings (appendix 12c).

3.8 Sampling Strategy

The sampling research methods used in qualitative inquiries are well distinguished from quantitative research that use methods such as random probability sampling with the aim of producing statistical inferences, (Creswell, 2019). To ensure that I could learn about the meaning and practices of health in the daily lives of Caribbean and African people I needed to ensure that my sampling strategy could gather a diverse group of Caribbean and African people. To accomplish the research, it was necessary to identify an appropriate and manageable sample of the population (Carlsen, 2011) that was able to respond to the research question.

Critical case sampling was used to recruit participants to the public consultation forum over four targeted events. It is an exploratory technique generally used in qualitative research and enabled me to make logistical generalisations from my findings to a wider population of people with similar characteristics (Emmel, 2013). However, qualitative approaches to sampling have been criticised for being biased and based upon convenience samples and it was important to ensure that the sampling approach used was robust and provided an accurate representative sample of the population group being researched. The communities' gatekeepers I had built relationships with would refer me on to other centres that were typically outside of the area and whereby other people would pass on the information about the research to generate further participant-involvement.

Because my research location constituted majority Black populations, I was able to recruit both Caribbean and African people to these events. The sample did however contain majority women during phase one because most of my participants were in the 50-69-year-old bracket and were not working in 9 – 5 jobs. I adjusted for this in phase 2 by asking participants from phase 1 for an equal balance of both men and women and they responded to this request.

My purposive sampling strategy was informed by inclusion and exclusion criteria for the study. Some of the participants in phase 1 of the study also took part in phase 2 which meant that the same criteria were applied. Here are the characteristics required for inclusion or exclusion from the study:

Inclusion criteria

People able to take part were:

- Over eighteen years old
- Self-identified as Black Caribbean, Black African or Caribbean African descent
- Fluent in written and spoken English.
- Ability to consent
- Lived in Greater Manchester

Exclusion criteria

People ineligible to take part were those who are:

- Unlikely to comply due to cognitive impairment such as dementia
- Those who do not fit the inclusion criteria above

3.9 Ethical Considerations in Ethnography

This section provides the ethical considerations in the conduct of qualitative ethnographic research, it outlines how I chose the participants and my positionality within the study. The basic principle of codes of ethical research practice is the responsibility to do no harm to those participating in the study (Beauchamp and Childress, 2012) The nature of critical ethnographic studies is based on close contact with the research participants over a prolonged period and this makes these responsibilities and values particularly pertinent.

There was a plethora of ethical questions that arose when I designed my ethnographic research and I considered each of the possible implications on the participants. I ensured that ethics was embedded through the whole research process (Denzin, 2018).

All ethnographies require that the researcher consider the ethical practices and responsibilities in collecting, storing data and in reporting the results. As I went through the university ethics process and form filling proformas, I realised that I had to be creative in how I captured some of the ethical issues that I saw as dilemmas in critical ethnography.

Ethical considerations are paramount in qualitative research and ethics is listed as one of the eight criteria that constitutes a good quality study (Tracy, 2010). This study set out to embed the principles of good ethical practice throughout all my direct and indirect engagement with participants ensuring that the information they shared was treated with respect and in a confidential and safe manner.

Contrary to positivists epistemological school of thought that claims only scientific evidence is defensible, (Rolfe, 2006) the ethnographic qualitative researcher defines the participants' realities and interprets how the participant shapes society. This is a two-way requirement as the researcher is also an instrument or a data collection tool that will influence the outcome of the study. This has ethical implications because of the expectation that by spending extended amounts of time with participants in the field that relationships will develop as they share real life stories with researchers about how they live their lives. As these relationships develop, trust and friendships may form, leading to obligations or expected mutual exchange from participants. Critical ethnography carries an ethical responsibility that requires researchers to be committed to the uncovering of underlying and overt functions of power and privilege. However, there are ethical dilemmas that can create unique concerns that are focused around the personal interaction and relationship between the researcher, the research team and the participants. All involved in the research are primary data collection instruments and bring individual biases to the field that involve their own personal experiences. This personal involvement of self in the lives of the participants is unique to this form of data collection and one that requires the researcher to consider how their own experiences, own socialisations, beliefs and identities influence what they bring to the field. This will involve adhering to the ethical principles of autonomy, justice, beneficence and non-maleficence (Beauchamp & Childress, 2012) and ensuring that the participants' information will be always protected. This was particularly important because as a researcher from the community, I recognised that some of the relationships within the communities had existed before the research started and would continue after.

3.9.1 Confidentiality, Anonymity and the Ethnographic Setting

In all forms of research, the responsibility to protect the anonymity and confidentiality of the participant is paramount. Doing this can sometimes be

challenging but in my study, reducing the risk as far as possible was important to give confidence to those taking part. For me, this involved protecting the privacy of the participants by removing any identifiable information from their excerpts as soon as information was collected. I routinely used pseudonyms, codes and labels to identify participants and fieldwork notes (Spradley, 2016) throughout all of my writing and note-taking.

It is important to note that it is difficult to guarantee complete anonymity when research takes place in a public setting, however, phase one of my research was an open public consultation and I advertised where the focus group sessions would take place. The centre where the data gathering took place was in a well-established community centre in Central Manchester and was used because it was known as the hub for those communities. My main priority was to protect the information that the participants shared during the focus group sessions and to ensure that each participant adhered to the rules around confidentiality, respect and value for each other's opinions and perspectives.

During my time in the field, I was often faced with some ethical dilemmas due to the immersion that I had in the field with participants. I came to know my participants very well and although I knew their stories would be beneficial to the study, I was faced with a decision regarding whether to include the information as a publicly available document because I could not have always guaranteed full anonymity, potentially compromising the identity of the participant.

The issue of consent for participation in research requires researchers to be fully transparent about the participants rights to be or not to be involved in research and that this is voluntary. Researchers should make it clear verbally and in writing that individuals should have free will and not be coerced persuaded or bribed to participate (Green & Thorogood, 2018). For the focus groups in this study, participant information sheets and consent forms were used. These were read to the participants during each session. Everyone involved in the focus group sessions was asked to complete a consent form (see appendix 6) to give permission for recording their views in relation to the activities.

Informed consent is a central principle in research ethics and is a voluntary agreement to participate in research with a full understanding of the research and the risks associated. Informed consent needs to be taken before any data is

collected (Salkind, 2010). During one of the weekly focus group sessions, one of the participants refused to sign but wanted to take part. I wrote about this experience in my fieldwork diary.

In my study, informed consent was acquired prior to the start of each of the weekly sessions using the consent forms provided on each table by the research helpers. Each participant was openly reminded of what they were agreeing to participate in and the right to withdraw their participation from the study at any time without any penalties. Each participant had a participant information sheet (see appendix 7) at the start of the session and each of the research helpers were able to understand the information and support participants to complete the consent form. Participants were able to ask questions about the study and to raise any concerns during any part of the session.

I informed attendees that were using the centre for their own social activity and not for the research study that they would not form part of my data collection or be included in any part of my research. The community centre lead had also posted flyers around in advance of the study to ensure users of the facility were aware and that they did not need to be involved.

Regular visitors to the community centre were informed by the staff of who I was and that I was there to run a two-hour communities' research project. They were told that I would be getting involved in some of their activities once the two-hour session had ended and that I would also spend some time making notes. I was aware that my ethical responsibilities extended to all the people attending the centre and that they could inform me if they did not wish to be involved in the observations or discussions.
As with any research study, there are ethical considerations that require careful reflection as to how the researcher will ensure doing good and avoiding harm (Beauchamp & Childress, 2012) to the participants because of the research.

The safeguarding of the group was negotiated with participants at the start of each of the targeted events. During the first session, I identified some ground rules for conducting the sessions which was centred around privacy and confidentiality and respect for each other's contributions. This was included on each table and each group was reminded about these rules at the start of each session. As phase 1 sessions was conducted as an open forum, these sessions needed to take

account of people arriving late at the focus group sessions and therefore being made aware of the ethical practices to which they needed to adhere.

Another ethical aspect that I considered was the voice of the participant and how this was represented by me the researcher. From an ethical perspective, I wanted to ensure that I did not diminish the voice of the participant and that there was an equal balance of power in the transaction between researcher and participant. In enabling this empowerment to take place in communities that are often misrepresented and disempowered, I ensured that I used their voices verbatim in the findings chapter of this research. In addition to this, that equal balance of power was demonstrated with how I co-produced knowledge with the participants. During the final week of the session, I spent time with the participants and the research helpers, crosschecking the overarching key issues that were generated over the 3 weeks of conversations and asked them to discuss how the issues should be prioritised.

As part of critical ethnography, an ethical responsibility and commitment to the researched is paramount. It was important that I explained to the group that I was committed to using the findings from the research as a way of raising their voices and sharing the recommendations with health agencies in Greater Manchester.

3.10 Demographics of Participants in Phase 1

There were a number of participants that had been employed in the health, social care or council services as support staff. Four of the participants were retired nursing sisters, one was a practicing psychiatrist and one was a practicing pharmacist. A retired councillor, a retired social work manager, two community development workers, three youth workers and two police support officers also attended the session. Four of the participants ran voluntary and community services across Greater Manchester. The remainder of the participants worked in industry across retail, catering, leisure, factory work and domiciliary care agencies. Others that attended were carers of their family members or unemployed. In appendix 3, I include the register template and the completed demographics (appendix 4) (table number, age, gender ethnicity) of those contributions I included in the data. These were coded from the register during each session and were used to identify participants.

3.11 Setting the Scene for Phase 1

During the homework phase, we agreed that the session would take place between 11am and 1pm to allow the participants time to get to the venue. We also agreed that it was important to have lunch following the focus group sessions to allow the participants to have social and networking opportunities. It was also important as a researcher to spend some time gathering stories and any additional information that would aid my study. Food is considered a very important aspect of engagement with these communities as it is very much a social activity as stated by the Pastor of the community centre. The importance of the 'ritual' of communal eating is an important cultural marker for the 'field' because it creates a space for:

> Eating and drinking [and] nourish[ing] an individual but also serves as a means to reconstruct communities and identities... (Beushausen 2014:11).

3.12 Data Analysis

In this final section of this chapter, I articulate the process I used to analyse the data to inform new knowledge and theory within this study. I did not have a specific theory that I wanted to test, instead, I wanted to know what it was like for the participants accessing the health market in an urban area of Greater Manchester. Although I had my own ideas about what it was like as a Black person accessing the health market, I used an inductive bottom up approach because I wanted to focus on giving voice to participants' lived experiences and to develop knowledge from their reality rather than to theorise and hypothesise in a deductive way. Through this data collection and analytical process, I was able to capture an understanding of the lived experience of Caribbean and African participants from the group consultations and the focus group interviews. Alongside this, it was important that I was not entirely shaping this study independently of the participants; I wanted to understand their own reality whilst also using the opportunity to cross check and validate the data. It was important to take my time with the data and to respect it for what it was and to ensure that I did not overlook what I wasn't expected to find.

The data analysis process was informed by an analytical framework which included the thematic analysis bottom up approach, outlined by Braun and Clarke (2006). Thematic analysis is described as a non-linear process that moves forwards and backwards to identify, analyse, and report themes and patterns within data (Braun and Clarke, 2006). It involves an iterative process revisiting the data sets backwards and forwards. The aim is to get from this point which was time consuming and messy to develop a map that identifies important themes. This six-phase model outlines the phases used to enable me to familiarise myself with the data (See diagram 6 below).

Diagram 2 - Thematic analysis process - Braun and Clarke, 2006

Although I recognised the benefits of using a software programme such as NVivo, I decided to conduct the whole process manually. Part of this decision stemmed from my preference, I realised that this software would not provide me with the deep immersion and sense-making I wanted with the transcripts from the beginning of the data collection process.

As an ethnographic researcher in this study, I wanted to be close and immersed in the data to gather depth and meaning from the data. I comprehensively transcribed the participants voices in full from the audio recording verbatim and analysed the data gathered from flip charts which included four weeks of consultations in phase 1 and then the six weeks of phase 2 focus groups. In order to become familiar with the data, I spent hours listening to the data until I became familiar with it. This included trawling through all the things that were said during the session. Transcribing after each focus group session helped to inform subsequent sessions as it enabled me to identify issues that needed further exploration in the following sessions. I used flipcharts to identify the key things that people had said and started to put those in categories which were renamed and reorganised throughout the analytical process.

Once I had transcribed the data verbatim I analysed the data by examining and interpreting the qualitative data to make sense of what it signified. Coding has is a process of assigning labels and organising data to identify different themes and the relationships between them (Given, 2008). I did my coding by creating tables in word document and then spent time matching the code to the relevant section that the data referred to This was a rigorous process of reading and re-reading the transcripts to generate codes. Once I coded all of the data I then began to collate all the relevant sections that fitted into that code. It was a very daunting task being faced with some much data, I had many pieces of paper, lots of categories, codes and colours everywhere. I finally reached the point where I could reduce these into hierarchical relationships.

Although I read and re-read the transcripts over and over again, it was very challenging to group the issues highlighted because they featured so many of the same overlapping issues and challenges that highlighted the concerns around oppression and disadvantage. The data was coded and eventually organised into themes in line with each of the statements, as I identified some key issues of interest in the data.

I identified the reoccurring statements and used those to develop broad categories and subthemes. From here, I was able to attach labels and identify the experiences of Caribbean and African people health; this was not a straightforward process but one that involved naming and renaming. I decided to use quotes to formulate the subtheme labels as these captured some common issues throughout the focus group interviews. Using the quotes directly from the participants was important as it made clear their experiences and left little opportunity for the researcher to misinterpret using their voice.

After three weeks of data collection, I used week 4 to involve the participants in the analysis because I wanted them to co-own the data that was produced. This joint thematic analysis carried out in week 4 with the communities aligns with the process outlined in Braun and Clark (2006) (see diagram 6). I brought the data analysis to the group and presented the main themes that were generated over the 3 weeks. This was used a process for checking the accuracy of the data that I had analysed from the three weeks of discussions. During week 4, I asked the participants to rank

the themes that were generated and the prioritised themes that were selected were then used to start conversations during phase 2 of this study.

During phase 2, I transcribed the data from the focus group interviews weekly and provided the group with some key issues they had shared from the previous focus group discussions. By allowing this to happen, it ensured that I wasn't directing the research but that their experiences guided the focus group conversations. I wanted to ensure my participants across both phases of my study were part of the analysis so before the evaluation session (see appendix 2 for evaluation form) during the final session of each phase, participants were provided with some key common areas that were developed over the weeks.

During phase 1, I supplied a numbered register on each table with the consent form to gather details of each participant (see appendix 4). It was a lot easier to manage the spoken voices in phase 2, however I attached a participant name to each of the statements made so that I could identify the voice of each participant, where and when it was communicated. At the end of phase 2, I was able to develop a thematic map which detailed relationships between the themes from across the two phases of the study.

By the end of the data collection process, I recorded a total of ten weeks of audio recorded conversations and transcribed twenty-three entries. In addition to those forms of data collection, I made 16 diary entries and excerpts that were relevant to the findings that are all located in the appendices (Appendix 12 a-e).

3.13 SUMMARY

In this chapter, I present my philosophical positioning and what tools guided my research question to enable me to gather the ethnographical data. I discuss the methodology, tools and sources of data that were collected to help me to access the knowledge. I state why a critical ethnography approach was necessary to hear the voices of marginalised communities and to suggest what could be done about the health disparities. I use the theoretical lens of CRT and intersectionality to understand what it is like to be Black and to access health care in the UK whilst being reflexive on my positionality and how all of this influences new knowledge.

I have provided a discussion of the research process detailing how I gathered and analysed the data for this critical ethnographic study. There are three phases to this study: The pre or homework phase, phase 1 and phase 2. Throughout, I demonstrate the importance of personal engagement with the communities to examine the culture and gain knowledge to enable action.

Chapter 4

PHASE 1 – FINDINGS

4.1 Introduction to the Chapter

This chapter reports the findings from the analysis of phase 1, which involved a consultation with Caribbean and African people (based in the UK) around health prevention information. In this first of two data chapters, I present findings collected through focus groups and some of my fieldwork diary captured in the appendices (Appendix 12 a-f). I interrogate the findings further in my synthesis chapter as I will provide a critical commentary of the participants' quotes. However, to foreground the voices of the participants, this chapter aims to merely present the thoughts that they shared with me on their own terms.

During this phase, I was able to access, engage and include a diverse range of intergenerational voices from Caribbean and African people who came from different parts of the Caribbean, Africa and the UK. It was extremely important, that these voices included their views of a selection of health prevention information, their explanations of what shapes the health information and with this, their experiences regarding what they perceive as barriers to adopting health prevention behaviours. This phase therefore aims to answer this first research question:

Research question 1: How is public health information understood, made sense of and experienced in the lives of Caribbean and African people in this study.

These findings revealed 3 overarching themes that were developed from the data through thematic analysis:

1) Encounters with Health Prevention Information

2) Obstacles to Health Engagement

3) Significance of faith and culture in health decisions.

I use snippets of verbatim quotes from the participants as labels for the subthemes. I was able to choose these verbatim quotes from my cross-cutting thematic analyses, where I had already arranged my themes and quotes into

distinct categories. The process used to code the participants voices is located in the methods section of chapter 3. The table with the participants demographics and assigned codes can be found in appendix 4

Footnotes are used to clarify local or cultural dialect used by the participants during the focus group sessions. Table 4 presents a chart of the three overarching main themes and subthemes explored.

Encounters with Health Prevention Information	Obstacles to Health Engagement	Significance of Faith and Culture in Health Decisions
"Feeling Ignored"	"Help us make sense of health information"	"My culture and faith counts"
"We are here but where are you"	"There are certain ways we do and say things"	"I need practitioners to understand me"
	"We are not all the same"	

Table 4 – Phase 1 Overarching themes and Subthemes

4.2 Overarching Theme: Encounters with Health Prevention Information

This theme highlights how public health information made sense in the lives of participants. This involved focusing on a selection of health prevention information given verbally by the presenters in the form of leaflets, which participants were asked to provide their views on during the first three focus sessions (see appendix 1 a-d). This theme captured voices of the participants when they spoke openly about how they were unable to relate to the information and the challenge to access meaningful health information. Participants shared how this influenced how they engaged in prevention behaviour and what their experiences of the barriers were to activities to reduce risks to their health. Throughout the

discussions, they suggested ways in which they could become more engaged in health prevention.

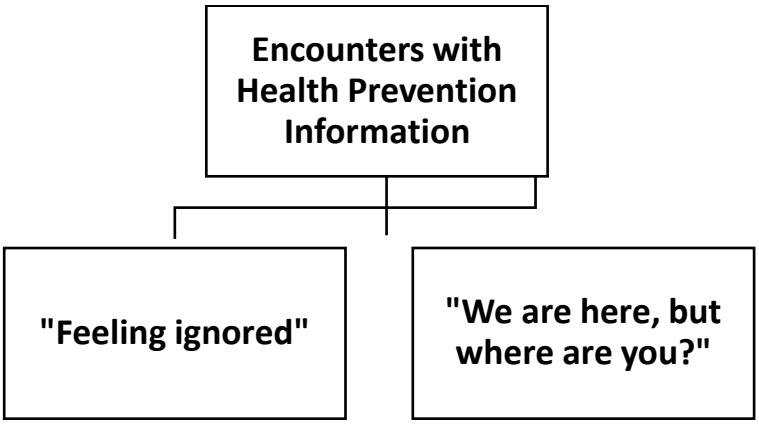

Diagram 3 – Phase 1 Overarching theme and subthemes 1

4.2.1 Subtheme 1 – 'Feeling ignored'

This theme summarises the experiences of participants revealed in the data. Participants saw themselves as absent in health information and spoke about ways in which the leaflets and the overall messaging did not resonate with their communities. They commented that information tended to focus towards meeting the needs of the majority population that led to them "feeling ignored'. They spoke about the missed opportunities to fill the vacuum with culturally relevant and relatable health prevention information that could engage them in health prevention activities.

During the focus group discussions, some of the participants spoke about the importance of getting health information that they could engage with and act on. One of the older participants sat flicking through the stroke leaflet and said:

> You know stroke is a big concern for Black people, many people in church die from stroke but still there is very little information in here directed towards us. (B3: 40 - 69 years)

Another group was also discussing the stroke leaflet and they too spoke about feeling excluded from the information because many knew about the threat of

having a stroke. One of the women who brought her mother to the group a few times and shared that she was caring for her mother who had a stroke 3 years ago. She said:

> To be honest, many of us know that stroke is common in Black people but still look, this [Stroke leaflet] was clearly not written with us in mind. I mean, what about us really, they [health professionals] know that we are at risk. (C6: 40-69 years).

During one of the planned weekly morning sessions (see appendix 1c) the PHE System leader gave a short 15-minute presentation about the One You campaign launched by Public Health England (PHE) in 2016. This campaign was developed to encourage adults to make small lifestyle changes to improve their health and wellbeing (PHE, 2016). The presenter started by asking over 40 participants to respond to a question:

> Presenter: “Raise your hands if you have heard about the One You campaign and tell me where you heard about it?”
>
> Participant: “I saw it when I was putting petrol in my car.” (C3: 40 - 69 years)
>
> Participant: “I heard about it through work because I work in a health care setting.” (C4: 40 - 69 years)
>
> Presenter: “Oh, I am very surprised because the adverts for the campaign have appeared on billboards, petrol caps and other marketing platforms.”

Only two participants had heard about the One You campaign and questioned how relevant it was to the Black communities. One participant said:

> The information is not hitting our communities, if this campaign is about the best ways to prevent poor health then we are missing out, looks like this is the first most of us have heard about this. (D4: 40 - 69 years)

Following the presentation, the presenter spoke about some healthy lifestyle practices such as healthy eating, exercise and recommended sleep for good wellbeing. Most of the research participants expressed that their lifestyle practices did not leave room to consider the suggestions such as exercise and 8 hours sleep because they were juggling lots of jobs to make money to support their families here or back home.

> To be honest, outside of making time for church I rarely get the opportunity to do anything else other than working. That time with God

> at church is so important, how can this be incorporated into this campaign as something good for people. (A5: 40 - 69 years)

Even though many of the participants knew the right thing to do was exercise, eat and sleep well, not smoke and drink too much they highlighted the need for specific education around how to implement these in a way that targeted their communities.

> It isn't new the need to do all this healthy stuff but what I am not hearing or seeing is how we do all these things in a typical day for someone like me. It is all good for those that have regular working hours come home, cook dinner like on that plate you showed to us, go for a run then to bed…. how many of us Black people here do that? (A1: 40 - 69 years)

One Nigerian middle-aged woman told a story about a typical day in her life that left no time for exercise.

> 6 days a week I go to Trafford park to do cleaning job at 6.00 o'clock in the morning. When I get back, I wake the children and get them ready for school. By the time I return home, I have not even had breakfast and it is already 9.30. I finally get to sit down and then I get a little something to eat and then I am off again to do work at the school as a play time assistant. From there it is home or shopping and I am exhausted before going back out to pick the children from school. I make the dinner, then by 6.00 o'clock until 9.00, I am back on the bus to work in the city centre cleaning. Just Wednesday evening and Sunday is the only time when I will not work because I go to church meetings. When I get home, there is no-one there to help, apart from my 16-year-old daughter that will look after my little ones when I'm at work [Life is] ah. (D5: 40 - 69 years)

Although the women that commented highlighted similar challenges of bringing up children as any other single parent, some of the older women spoke of the further disadvantages due to limited support networks from immediate family that were able to help. This prevented many of them getting involved in what some others in another focus group called 'extracurricular' activities such as exercise. One older mother who had 6 children and a single parent who sat on the same table commented

> I guess it is just one of those things that many of us did, we just worked all the hours God gave us strength to carry out, we didn't think about the way it was going to affect our health at the time and no-one warned us to do to things differently, we just did what we could for our families,

> it is now that we are older we are paying the price with our health. (D2: 40-69 years)

She went on to say:

> The stress it caused and still causes is the thing that I think is killing us off, and we are expected to keep going. Things have not really changed much for Black women, where is all the health prevention about the stresses Black women face? (D2: 40-69 years)

The 'One You' campaign recommends small changes to people's lifestyle such as increasing exercise activities and suggested eating plates. Participants agreed that there were benefits of exercising and healthy eating, however, they expressed that their social and economic circumstances did not allow them to adopt the suggested better ways to wellbeing. They felt that these recommendations given by the PHE presenter such as joining a gym were unrealistic for a lot of people in their communities. One of the participants pointed out:

> These are great recommendations but not for me, this what you are saying here is largely focused upon those that are White middle class. (D5: 40-69 years)

The participants referred to how they saw the information as being based upon a typical individual and not Black people. I asked a couple of questions when the groups were discussing the presentation and the health prevention leaflets:

> Me: "so, do these leaflets discourage you from reading them?"
>
> Participant: "Ummm, well it does, really. This is because you see it and the information doesn't resemble anything about you or the way we as a people do things……"(A1: 40 -69 years)
>
> Participant: "It is a shame really because we come from a place [Jamaica] where everything we saw and read was about Black people, you really notice the difference here and even though I have been here over 40 years, it still troubles me that the information is still not speaking to me." (A6:40 -69 years)

Participants' claims that the health information was focused on the majority populations resonated around the room and many suggested that this had the potential to prevent engagement with health prevention activities. They spoke about times when they had asked for information but that was ignored. One

participant (with whom many others in the group agreed) believed that they often receive poor and substandard information and care because of their race.

> It is so upsetting and devaluing, I have been so unhappy at times with how I have been treated as a second class citizen when I ask for information. I am often ignored, I mean, I am there physically but you can just tell by their body language and facial expressions that they have no interest in what you are asking which I guess wouldn't happen if I was White. It is like they see you as underserving. (E2: 70 - 85 years).

One participant supported this and spoke about how disrespected she felt when She had her first baby and wanting some support from a midwife

> I could not get over the way the midwife ignored me when I rung the buzzer for help after my caesarean section…it was like I couldn't believe it, the buzzer was going and I thought she came to help me but walked straight past me and went to help the White lady who wasn't even ringing for assistance…I felt so undervalued, I felt like nothing...ahh

Another health prevention tool and presented as a part of the One You campaign, The Eat well guide (see diagram 4 below) was presented to participants during the consultations. This UK health prevention tool was selected as its aim is to reduce the risk of health conditions such as strokes, diabetes and hence increase life expectancy through healthy eating.

Culturally appropriate material around cardiovascular related disease was not readily available in Manchester during the time of this study despite trying to obtain this from across GPs and community health clinics. The participants' everyday concerns about their own health was important to them, however many of them stated that PHE did not tailor health information to diverse groups. Each group unanimously shared similar perspectives on the Eatwell Guide and the lack of reference to their own cultural foods. Participants stated that it would have been easy to add a selection of representative foods from across different cultural traditions. In reference to the eat-well guide, one participant stated:

> This is another thing that does not cater for our cultural foods, this is basically English foods on here with no yam and bananas……. there

would be no harm our own foods being included and being told to eat them in moderation. You see, they are dumplings that we eat a lot of, and they are really heavy, what is the substitute for dumplings that will help us improve our health. (C3: 40-69 years).

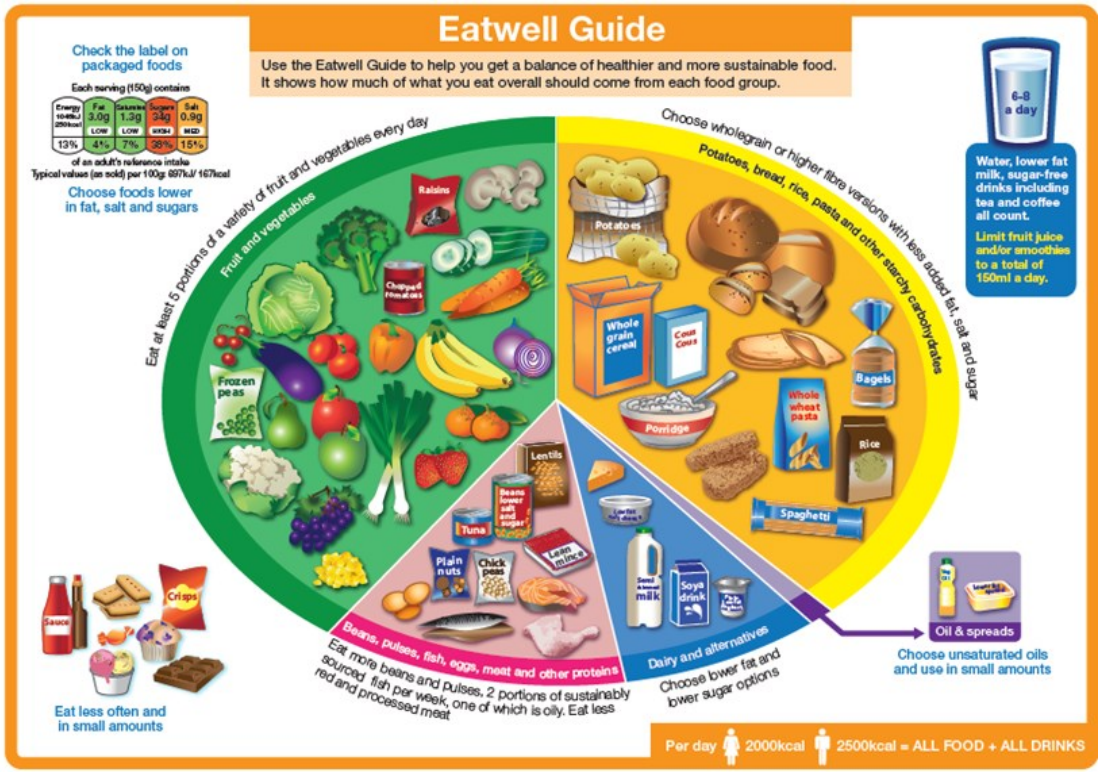

Diagram 4: Eatwell Guide, Public Health England, 2016

Other participants agreed and some were quite sceptical about who the leaflets and campaign information were designed to benefit. They spoke about a missed opportunity and that the information could have had some reflections of their culture in the leaflets:

> There is something about the leaflets, really feeling ignored and neglected as a people right now, a few images and some of what we eat would help. (C4: 40-69 years).

This gap in health prevention information led to the group to discuss the issues around trust and how it features when engaging the communities especially when information does not address them or consider their overall needs in health prevention and guidance.

An ex-nurse spoke about the importance of a healthy diet and highlighted how food is a crucial part of the prevention of poor health. She stated that a lot of the literature talked about the ways in which health prevention of heart disease, strokes and diabetes etc. is largely centred on what you eat and how much.

> Information we are provided with is not appropriate to be preventative it keeps Black people in poor health ……. It is almost like we have been here too long for them to think they need to do anything different for us. (C4: 40-69 years)

She went on to say:

> The right food is wealth, and we need it to keep us healthy. Having information about good healthy traditional food is also important but we do not hear about that. (C4: 40- 69 years)

A good illustration about the differences between the UK and the Caribbean was expressed from one of the older women who in her conversations was quite aware of the importance of diet and exercise but recognised that it was not the same for everyone, she said:

> When we were back home, we could eat fresh food, we didn't have all of this processed stuff. Also you knew that you would walk off whatever you ate and the heat would also help you to sweat out and burn up calories. Here it is so different, we tend to be so much bigger and we don't sweat our food out. (A6: 40 -69 years)

One of the participants stated:

> It has been really difficult recently because we lost another sister in the church and you know, there is a part of me that blames the health care staff for many of the people we have lost; people dying from things like diabetes when it may have just needed some health information directed at us. We are not experts, we need the education! (D1: 40 - 69 years)

It was apparent from some of the discussions that Black people should take some initiative and find ways to do healthy activities. One participant that joined in week 3 was a pastor, health professional and a community organisational-lead who wanted to see our communities take some responsibility for their own health. She shared what used to be organised from her church

> As a person of faith and a health professional, I used to arrange prayer walks as I encouraged people to engage in their spirituality and attend to their physical health. (F1: 40 -69 years)

4.2.2 Subtheme – "We are here, but where are you"?

This theme reverberated around the room as participants expressed the need to have direct face to face health prevention education from health professionals and much more visibility on the radio and other communication platforms. The participants emphasised that they were not hard to reach and needed specific information because this was missing within leaflets and other health services they accessed. Some of the participants stated that they wanted health professionals from their own communities to provide information because they believed that they could relate more easily to them.

While there was consensus among some of the participants about the need to act and do things for themselves, there were others who questioned this and said that providing appropriate and specific health information should be something accessible to them from health professionals within the health service. They wanted to know why health professionals were not visible in their communities or even on the different communities' radio stations when they knew that their communities were known to contract a lot of health problems. One of the men in the group said:

> You see if they were truly concerned about all of these health problems we have then they would pay more attention and try to stop us getting them in the first place, they tell us we are hard to reach but we are here, but where are they, look here, there are at least 40 of us in this room right now. (F2: 40 - 69 years)

One younger male participant born here in the UK but of Jamaican background said that he found it difficult to put the lack of health attention down to anything else other than being Black. He spoke about times when he approached services for information and felt dismissed:

> To be honest, I can only put all this down to the colour of our skin otherwise why wouldn't they spend more time with us! (C1: 18 - 39 years).

One Jamaican woman who joined in the conversation agreed and said:

> I used to be a member of the Sugar group over there in Moss-side when we had the old Primary Care Trust……we would make several requests for health professionals to come and talk to our people about how to look after yourself. Every time we booked a session, it ended up being cancelled because they were short staffed and were needed elsewhere, it was interesting how they never offered alternative dates. (C6: 40-69 years).

Through discussion, it was apparent that several of the participants were aware of the need to adopt healthy eating and exercise to reduce their chances of getting conditions such as cardiovascular related disease. However, there was a discussion about the importance of getting correct information from professionals about the ingredients, so they could adopt good habits before people ended up with health problems. Some of the participants stated that they did not know that coconut cream was bad for the cholesterol. One member of the group indicated that it was their family and cultural influences that informed their cooking practices:

> I used to watch my mum pile loads of coconut cream in the pot with the peas on a Sunday and for years I never thought anything of it until I met this Black woman at uni who said how bad it was for you ..…. we need some proper education because it wasn't just my mum doing this most of us did adding with it the butter and plenty of salt and seasoning in Sunday dinner. (C6: 40 -69 years).

One woman went on to say:

> It is so important to get the ingredients in cooking right, it is a cultural pressure but not good for your health, some education about this would be helpful. (B3: 40 -69 years).

In one of the focus groups that consisted of mainly older people, the participants said that it was very unusual to have access to health information at church but stated it was something they had started to see take place across Black churches. They spoke about the limited time they received at the GP surgery and although infrequent, they said the information they received at church was very

helpful with lots of relevance to them with common health conditions in their communities.

One Jamaican woman spoke about a session she attended recently that was arranged and provided by nurses in her church. As she shared, and I reflected when I got home, I felt incredibly sad that these sessions had not happened sooner for these communities. I write about this in my fieldwork diary (see appendix 12d).

The participant said:

> I have been here for 50 years and now I am in my 70's. I have diabetes, high cholesterol and high blood pressure. It is only now in church when some of the church brethren arranged talks about health, it was so good. (B5: 70 - 85 years).

In the groups, participants expressed a real desire to learn about how to keep well and prevent some of the illnesses their parents had suffered from in this country. Conditions like diabetes were cited as a big problem for people in the communities and they discussed some of the dietary challenges. One gentleman wanted to emphasise his point about leaflets and face to face information and dialogue. He said:

> Leaflets on their own are not all that helpful, we need the opportunity for discussion, time with people that know what they are talking about is important especially when information for us isn't readily available. (E5: 40 -69 years).

Participants continued to emphasise the importance of how they accessed information and who from. It highlighted that in many cases being given information from someone that looked like themselves in terms of skin colour would often encourage the participants to access and trust information.

> I think it is very important …. to be able to hear from people who look like you and someone that may have gone through something similar as you or even asked the same questions as you. It can be easier sometimes because they understand where you are coming from and you don't appear stupid. (B1: 40 -69 years).

Another participant agreed:

> To be honest, the information just seems to sink in a bit easier, they speak to us like they are your family. (B1: 40 -69 years).

This provoked quite a lot of discussion on this focus group table which had several middle-aged people.

> For me, I see Black people and I do not need to pretend or be careful or wonder what they are thinking about me. (B4: 40 -69 years).

This overarching theme highlights the experiences of the participants and their encounters with health prevention information. Part of 'feeling ignored' was an important aspect of the way that Black people experienced health care with some looking at ways in which they could help to fill the gaps left by the mainstream health providers. Participants felt that the information they received during the sessions that were publicly available and those encounters with health care providers were not conducive towards health prevention and adequate care that respected them as Black people. "We are here, but where are you"? provides accounts of the participants who clearly articulated the lack of visibility of health professionals in their community. They spoke about the need to have health care providers becoming part of their education and prevention activities and ideally highlighted the need for cultural sensitivity provided by working with people that looked like them and who understood their needs for health.

4.3 Overarching Theme: Obstacles to Health Engagement

From the earlier themes, it was evident that the participants saw gaps and missed opportunities for embedding cultural, religious and lifestyle factors in the messaging. This theme has overlaps with previous subthemes but discusses the obstacles to obtaining health information that they could use and benefit from in order to improve their health. It also discusses other obstacles such as the culture, language and generational differences that prevented them from getting the most of our health care. There are three sub-themes related to this main theme, see the diagram below

Diagram 5 – Phase 1 Overarching theme and subthemes 2

4.3.1 Sub-theme 2 "Help us make Sense of Health Care Information"

This subtheme expressed the participants' struggle to make sense of and get the most out of health information. They expressed that because they were not given the necessary information from health professionals, they found it difficult to get the most out of the overall health care experience. For many of the participants, they talked about how this resulted in an exacerbation of their health problems and later engagement with health professionals because they did not understand the overall health issue.

During the focus group discussions participants expressed that when they were presented with information from GPs and health professionals about health, they were not always knowledgeable about the condition or given treatment options. I refer to this in my fieldwork diary, (see appendix 12e). One participant said:

> What I find is that when I go to the GP for an appointment, I am not given any detail about the condition they have told me I have, it is then difficult to know how to manage the problem. (F3: 40 - 69 years).

One woman was quite emotional as she spoke about something that had happened to her which stemmed from a lack of information:

> When I was in my early 30's, I just never spoke up, I was one of those people that just took what people like doctors told me and didn't question anything, I guess it was something that stayed with me from my school days. One day that backfired on me and I ended up having an unnecessary hysterectomy for fibroids and now I cannot have children. Although I take some responsibility, it creates a lack of trust

> when they [health professionals] don't help you make the right decisions about treatment. (A3: 40 - 69 years).

Participants did not view the information as hard to understand or interpret when they received it, however, they stated that there was the lack of information that they could make sense of so that they could make informed decisions, in the first instance. This was echoed as particularly important for preparing people in their recovery.

The woman that had the hysterectomy said:

> I can honestly say that I did not get half the time that I see others getting with the nurses. When I was being discharged I could hear all of the explanations being given to the woman behind the next curtain to me but when it came to me being discharged by the same nurse it was so quick and I was given so much less information about what to do if……I was treated as lesser than the other White woman. (C5: 40 – 69 years).

One of the participants in another group that consisted of ex-health care professionals said:

> You see I do not think we go prepared for our health appointments and treatments, and there is little out there for many people that have not been trained like me. I can honestly say that I make the most out of my appointments with the GP, I will ask every question until they are fed up of me. (C7: 70 - 85 years).

She went on to say

> It is so difficult to know what to ask when you do not have all the information about what it is that is happening to you. We need advocates to help people, so they get the help they need, as they say, you don't know what you don't know. (C7: 70 - 85 years).

Overall, participants were more concerned about the fact that information did not seem complete to help them to explain what was wrong with them. This is an important point because this is not a result of low knowledge of healthy behaviours and eating but about how the information was shared.

> We have so many radio stations in our communities and it would be good if we had health professionals going on there to talk about health prevention in our communities. They have a duty to help us make sense of health information. (E2: 70 - 85 years).

One participant told the focus group about a time when she was referred to the hospital for an appointment with a consultant and could not fully explain what her GP was treating her for:

> Well, it was so embarrassing, I turned up after and the consultant started by asking, so what has been going on. I could explain what was going on for me physically but could not explain for the life on me what the GP said the problem was and what the medication was for. The thing is that I don't trust getting information from the internet so rely on the doctors to tell me; what is frustrating is that when you ask questions, they look at you as though you should know so you don't ask. (A3: 40 - 69 years).

One of the women who also had a recent experience with her GP said:

> It's true, you go there, and you feel that no-one is listening to you. They almost fob you of in a rush to get through to the next person. I don't think it is deliberate, but they seem to treat Black people like dem nu have much sense.[19] (A6: 40 - 69 years

During the session, it became apparent that the frustrations at the lack of information to help them get the best of out of services led participants to seek guidance from their own communities. Some stated that they just wanted the health information from professionals within the Black communities because they could trust them.

One woman stated:

> I want to know how we could package our own cultural food with nutritional guidance, as communities we have been here long enough and have enough qualified professionals to do this for ourselves. (F3: 40 - 69 years)

Another young male participant who supported the comment said:

> Indeed, look at all the health professionals in our own communities, we can create our own health services, why are we still engaging in these services that are so bias and don't even want to provide health prevention information for us. (F5: 18 - 39 years).

[19] This means that people do not have a lot of sense

This was backed by others but one of the participants talked about how the health service was set up in a way that treats us as second-class citizens. This participant who worked in a GP practice as a manager said:

> We need to work with our White health professionals so that they learn to give good and proper culturally appropriate care to Black people. If we do not work with the services to rid the prejudice and stereotypes that people have about us, then we will be here asking for the same recognition in 5 or 10-years' time. (D3: 40 - 69 years).

4.3.2 Subtheme – "There are certain ways we do and say things"

Within this theme, participants described how their cultural behaviours, expressions and language influenced the health care relationship. It is recognised by some that Black people are not homogenous, they come from different islands and have different cultural patterns and behaviours that need to be considered when providing care. However, regardless of this, the overriding factor in the way that Black people responded to health information and health service staff was very similar. It was expressed by the participants when looking at the material shared that there was a lack of attention and insight to the cultural behaviours and language needs. They stated that this lack of insight would lead to limited engagement with health professionals and more focus directed to their own communities and religious leaders for guidance and support. Participants identified the failure of mainstream services to recognise this diversity which was particularly relevant to older participants and those that had migrated to the UK.

Across the groups, participants stated that although English was their first language in many of the countries represented in the focus groups, this was not the case across all participants. One woman from Angola who had a very strong Angolan accent spoke about the assumptions made at her GP and others providing services

> It is interesting that when people look at you here and see Black, they just expect you to speak English. No-one ever offers interpreters. (E1: 40 - 69 years)

Even where English was the first language, participants wanted recognition of some of the dialect such as Jamaican patois which they said could be problematic when communicating with health professionals. They said that the Jamaican

dialect was not recognised by mainstream services as a non-native language. One Jamaican older man spoke about the 'twang' that made it difficult for them to be understood:

Yes, when mi say sic, they think mi mean sic like vomit, when I say mi head hurt, them tink headache but mi mean stress.[20] (F2: 40 - 69 years)

Some of the participants found it difficult to express themselves using English words about how they were feeling. This has been identified as a major barrier preventing people (especially the older generation from the particular parts of the Caribbean such as Jamaica and Barbados and some African communities) coming forward to engage with services for fear of not being understood and therefore dismissed by health professionals. This was largely a concern from the older generation in this group that came here in the 1960's. I make reference to this in my fieldwork diary as an observation that took place during the first week of the focus groups, (see appendix 12d)

> I will not go to any of my appointments without my daughter, I need someone to be able to hear and speak up for me otherwise they will not pay me any attention. There are certain ways we say and do things and it isn't ok for them to tell us anything anyhow. (B5: 70 - 85 years).

In the same manner, several participants within another focus group discussion also highlighted issues and concerns about language and found it challenging at times when it came to describe their symptoms. Some were put off engaging with health professionals and said:

> Mi go dere and dem nu hanerstand so what ada di point is dere in going, mi may has well just seckil mi sen an use affa mi own tings dem and sart mi sen out.[21] (E4: 70 - 85 years).

A Nigerian woman who spoke several languages said:

> It is hard to be understood by the GP or nurse when I go to the surgery, I find that I need to repeat myself so many times and yet I am still not understood, this is worrying when you go for help and they don't get

[20] In patois this means: when someone says they are sic, they mean that they are physically unwell rather than specifically feeling like vomiting. A headache is a metaphor for feeling stressed rather than a necessarily a specific pain in the head area.

[21] In patois this means: That she engages with health professionals, but the participant finds the engagement pointless because health professionals do not understand her dialect. This leads her not to engage further and find her own way of addressing her issues

> you, you wonder what they are actually giving you and what for. (A7: 40 - 69 years).

One of the participants agreed with the above and went on to say

> It is very easy for health professionals to say they will go and get an interpreter for someone who is Asian but when they see us [Black people] they hardly ever see that we have specific language needs too. My dad came from Cameroon 50 years ago and hardly speaks any English, he has a really strong French accent, they look at him as though he has no sense. (A8: 40 - 69 years).

Several participants across the groups did not believe that the health service provision was concerned enough to prioritise them and their language needs. In conversations, they said they had been in this country long enough for people to see the barriers that could be preventing them from engaging in health services. One of the African women said:

> The issue is that when it comes to Black people there are certain ways we react to things, we aren't going to keep going on and demanding this and that if they don't show any interest. (A1: 40 - 69 years).

The conversation led to some discussion on issues related to what they described as cultural behaviours. The women in the group talked about some of the cultural stereotypes surrounding Black women that deemed them to be loud and assertive. One woman said that some of what people say about us have changed the way we present ourselves in public:

> In fact, when you listen to Black people, we do tend to speak differently don't we, we tend not to be so forthcoming asking for things and we are a lot more reserved not sure why. (A3: 40 - 69 years).

Another woman said:

> That maybe so now, for me personally, I was sick and tired of being told that I was loud and too assertive especially in school, I am very different now and agree that I have become more quiet, I feel more vulnerable now. (A1: 40 - 69 years).

This sparked an interesting conversation and one of the women said:

> It is as though that stereotype especially those labelled against Black women have quietened us down that we cannot even come forward to share about some of the issues we have because of what people may think or say. (A7: 40 - 69 years).

Another respondent from another table overheard the conversation and stated:

> Our communities need to work on how we rid some of these cultural issues and stereotypes that are affecting our health……. Just look at mental health, these are not things we brought upon ourself. (B1: 40 - 69 years).

There was an expressed belief that there is a poor understanding about different cultural behaviours from health service providers and that this was a barrier which promotes disengagement with health prevention information and services. Participants recognised that this was not necessarily the fault of the practitioners and spoke about how the communities needed to be transparent about the issues that they faced and how they would often respond to health professionals. One participant who was particularly keen to express that there were cultural behaviours holding some communities back, said that she agreed:

> There is something that runs a bit deeper than just admitting problems in Black communities, we have been in such places where we are viewed so negatively and that is not just by health professionals but also by our own communities. Culturally, our communities won't just share our stuff with even our people and its stressful. (B8: 40 - 69 years).

4.3.3 Subtheme 3 "We are not all the same"

This theme was evident within all the focus group discussions and highlighted the differences between communities and across generational groups. These generational and cultural differences between Africans and Caribbeans especially born in the UK were quite distinct in relation to their perspectives around health and medicine.

The older people in the groups had migrated from the Caribbean or Africa and were not accustomed to readily taking western medicine. One of the older participants that migrated from Nigeria fifteen years ago stated:

> There are so many stories about the side effects of these medicines here, and I don't think my GP understands me and where I am coming from. There are generational differences and I would rather trust the medicine [traditional] that worked for my forebearers rather than prescription from my GP. (A7: 40 - 69 years).

There were many examples provided during the focus group sessions where older participants gave their stories about the lack of trust that resulted in their underuse of medicine. One participant said and many others echoed this practice

Every-time mi left di doctar dem haft fi give me something fi tek, I just put one pills pon di shelf and nu take dem and see me aright, nutin nu wrang wid mi… [everyone laughs][22] (C3: 40 - 69 years).

Even though several of the participants [especially older people in the group] came from the Caribbean and Africa where they often did not have the option of western medicine due to cost, they were still keen to explore the traditional medicinal routes to treat their illness. African people were less likely to adopt western practices than people from the Caribbean who in comparison tended to be more compliant with medication and visiting the doctor.

One woman from Angola spoke about this and said:

> We Africans are so strict in the way we do things especially our religion, we are less likely to comply with medicine, seek divine intervention for healing than visit the doctor. (E1: 40 - 69 years).

Another African man agreed about this and said that it wasn't only down to religion but also about migration and the way we still saw things:

> It took me sometime to really change the way I did things, immigration is a big issue because it's about access to medical people and even when our immigration status comes through, we are still in that mindset where we still don't engage. (E8: 40 - 69 years)

Participants were keen to understand the real benefits and properties of their traditional remedies and they were not sure whether the western medicines were suitable for Black people as stated by a participant:

> Research is needed into own cultural herbal remedies rather than just offered western medicines. (E4: 70 - 85 years).

[22] In patois the participant shares her experience which states that it is usual practice for GPs to hand out medication which she does not believe will work. She therefore does not take the medication but is able to recover

There was an interesting discussion in one group which talked about the lack of reference to herbal medicines in the health material. They did talk about hearing about some of the traditional remedies from the pharmacist who would talk about contraindications with western medication:

> A pharmacist spoke to me at church about not taking the Cerasee[23] with the blood pressure tablets, but I wonder why and is it not better to take the Cerasee and not the blood pressure tablets. (B5: 70 - 85 years).

There was a conversation in the room about alternative therapies and a belief in prayer as opposed to western medicines. Many (especially the older generation and those that had recently migrated from their home countries) understood that this message meant that they should refrain from taking western medication but others were keen to see some reference and acknowledgment of their herbal practices in public health material.

One African woman from Nigeria who did not know about anything other than her own home herbal remedies stated that every day she takes her own herbal drinks that she believes has kept her well:

> Western medicine does not suit Black people and that it [medicine] was 'killing us off'. (A8: 40 – 69 years).

Two other women echoed the same sentiments and stated that it wouldn't be something they would take easily.

> Medication is my last resort. (A8: 40 - 69 years).

> …and mi too, mi not taking dem fa me to feel worse dan me feel already[24] (A4: 40 - 69 years).

Some of the male and female participants that were born in the UK agreed with this and had also adopted some of the practices of their parents but not to the same degree. They were still reluctant to engage fully with western practices but

[23] A traditional medicinal herbal remedy native to Africa and used by Black people to improve overall general health and help to purge or cleanse the blood. Can be spelt as cerrasee or serasee It is usually boiled and drunk as a tea.

[24] This participant explains that she is not taking medication because she believes the medication will do more harm than good and make her feel worse than she currently feels

were more unlikely to take advice and medication without questioning their practitioner.

> To be honest, I might be quiet but I'm not just taking anything for it to cause all the side effects we hear about with some medications. (F4: 18 - 39 years).

Another group of younger participants were holding a similar conversation and discussed how the education they received in the UK made them more aware of what to look out for and be less trusting of medication than their parents. He said:

> I am so careful when I am prescribed anything these days, it is good to be able to google trustworthy internet sites for yourself rather than just accept what the doctor says. It's also good because in church I can check things with people like pharmacist and other Black doctors. (F5: 18 - 39 years).

Participants overwhelmingly spoke about the lack of time spent with them to help them make sense of health care information. They shared times when they received limited information without the detail needed to make sense of how they could implement a self-caring approach to health prevention. The point was made here again about utilising own Black health care professionals to support the education given to Black people to improve their health. Participants wanted to share the importance of differences across the different communities and the need for this to be recognised by mainstream health providers. They believed from their experiences that health providers just saw Black people as Black people and did not understand that Black communities did things differently, had different language and cultural needs that all impacted upon the health experience. Some of the participants recognised and noted the intergenerational differences and voiced internal cultural and religious challenges within Black communities that made it difficult for health providers to engage and that these could have been rooted in past experiences.

4.4 Overarching Theme: Significance of Faith and Culture in Health Decisions

The final theme that transpired from the data is a broad one that comprises key issues that influenced the participants' engagement with health prevention

information. This theme comprises wider contemporary issues that influence perceptions of health and how significant faith and culture is to people of the Caribbean and African Diaspora. Cultural behaviours and attitudes are often based on religious beliefs and these will impact upon how and whether people will engage with health practices and health services. Therefore, the influence of faith and culture on health was an important aspect highlighted by the participants especially among the elder participants in this study. The voices of the participants highlighted that although an understanding of health information about health conditions was an important aspect, the overriding factor in relation to how they responded was placed on how the participant interpreted that information from their cultural, religious context.

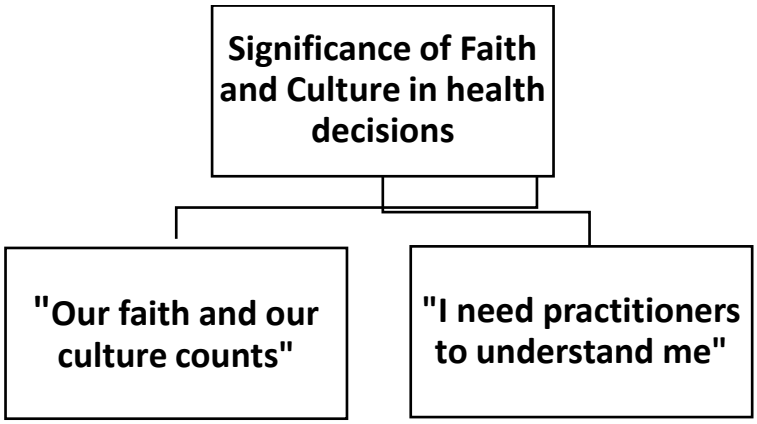

Diagram 6 – Phase 1 Overarching theme and subthemes

4.4.1 Subtheme 1: "Our faith and our culture counts"

This subtheme discusses the importance the participants placed on faith and culture in health care decisions. Faith and culture were especially significant to those that were brought up in Caribbean and African traditions. I refer to my experiences in my autobiography (Chapter 1) and how it was for me growing up. Faith is entrenched in the life of these communities and it directs many of the transactions they make about their health. Regardless of age, many of the participants in the study attended a church and had a strong affiliation to faith.

In the Caribbean and African communities, faith and culture is often the common denominator in decision-making about health. However, some of the participants commented that they believed that God provided doctors and other health professionals to be the tool used to help them in their treatment. One participant said:

> My faith is so important to me, I would always commence with prayer before going to use hospital services when ill, sometimes I have a word from God that orders me to stay home and pray instead of going to use health services. (A5: 40 - 69 years).

The faith of the participants was so strong that many would rely only on their faith to be healed, for some, this prevented them from engaging with health services. Their faith was often accompanied by the belief that the outcome of their illness was in the hands of a higher power. This belief was not always the barrier to participants engaging with health professionals but was a major factor in Christian decisions about their health.

One participant said:

> Pastor say that I should have more faith to get healing, he said I need to pray more and believe God for a miracle. (D6: 40 - 69 years).

Another participant agreed and stated

> You see, there is a powerful message about God being a healer, and that we need to have faith to be healed. (E8: 40 - 69 years).

Many of the participants regardless of their age were deeply entrenched in their faith, many of the younger participants were raised in Christian household and continued to live their lives according to the religious teaching.

One participant shared her story about unwillingness to undergo a caesarean section until her pastor had arrived to offer prayer and guidance. She said:

> Even though I was at risk of dying, I had faith to know that my pastor would pray and offer reassurance that the medical personnel would carry out the right procedure. (D6: 40 - 69 years).

Some theology is shaped by certain principles and some people fast and pray rather than see a GP and take medication. Participants expressed the importance of health professionals understanding some of the religious viewpoints that caused

people not to engage in health services because it was viewed by some as a sign of weak faith to accept illness. One participant who believed in God and medication to help become well said:

> I feel judged especially when it comes to medication. One church sister I was speaking to about my high blood pressure questioned why I was taking medication and told me that my faith wasn't strong because I took medication.

It was evident that participants agreed that the church was a powerful place to disseminate key health messages. The voices of the participants highlighted that although an understanding of health information about health conditions was an important aspect, the overriding factor in relation to how they responded was placed on how the participant interpreted that information within a religious context.

> God help us, we know that we suffer bad but many of us will not go to the doctor but go to the pastor instead. My pastor who is also a GP will help me to do both when I see him in church and quoting some scriptures really helps you know. (F5: 18 - 39 years).

However, going to the pastor first was not the case for all participants and a couple of younger to middle aged individuals were surprised by how much Black people relied on their faith to guide decisions. Although some participants saw engaging with health professionals and not trusting in God as a sign of weakness of their faith, two participants stated that religion was a way of keeping people quiet especially Black people:

> I don't think us Black people get it, religion has been imposed upon us, it was used to justify so much back in the day and I just don't get how so many Black people are letting this thing dictate to them. (F7: 18 - 39 years).

Another participant said:

> Some people think that all they need to do is pray then everything will go away without them doing anything, its' crazy really. (F6: 18 - 39 years).

One African participant who practised her religion devotedly said:

> For many of us, our faith and our culture counts, we have our own religion beliefs practices and when I feel that conviction and guidance

> from God, then that is the direction of travel I will take because I live my life by Faith. (F1: 40 - 69 years).

4.4.2 Sub theme 2: "I need practitioners to understand me"

This sub-theme found knowledge about cultural and religious practices to be limited amongst health professionals when providing care and information for Black people. It was recognised that the encounters participants had with health professionals and the reference points they used when giving health advice highlighted that there was a lack of insight into the importance of religious practices on health.

Participants expressed the importance of health professionals connecting with them and displaying a genuine desire to meet their health needs in a culturally and religiously appropriate way. I refer to my own experiences and an observation that took place during week 4 of the phase 1 focus groups in my fieldwork diary, (see appendix 12f)

Overall, when participants spoke about the health practitioners, they were keen to express that they did not in all cases believe that they had the intention of treating Black people unfavourably or intentionally ignoring their culture or religious beliefs.

One woman said:

> It is not really about the health professional themselves; this is more to do with the way that health professionals understand us and the way we do things. I think there needs to be something more specific that helps them to recognise the importance of cultural and religious practices for some of us. (E6: 18 - 39 years).

Although many of the participants put the limited insight down to a lack of understanding about their communities from professional staff, there were a few frustrations and participants said there should be adequate understanding of their communities by now, to provide care that is sensitive to their needs.

> We have been here in numbers for a long time now, we have not just arrived here, health service staff should be more culturally aware and be able to communicate with us much better. For me, my faith is what guides me every day, if they don't understand that then how can they provide care. (E2: 70 - 85 years).

Participants expressed the importance of health professionals understanding some of the religious viewpoints that caused people not to engage in health services and that it was viewed by some as a sign of weakness of faith to accept illness. Participants stated that this was important for practitioners to be aware of because it led to some people not coming forward for care.

One participant said:

> I personally do not agree with this because if people are feeling unwell then they are unwell, how can you deny something that is happening to you and then how can you get help. We often say that health professionals do not provide care and we sit there not coming forward and hide behind religion. (E6: 18 - 39 years).

Participants highlighted that there were some very important ways that Black African people do things that involves cultural and religious practices and these things play a part in whether Black people engage in health prevention:

> I appreciate that the emphasis on culture is not as important for everyone and that this often depends upon whether you were born here or if you had been in this country a long time. It should still be something that health care staff see as quite vital because it is how many of us live our lives. (B2: 40 - 69 years).

On one of the tables, a middle age man and his wife, who were both in professional careers spoke about the importance of culture, but they wanted to emphasise that their culture did not dictate their health decision. For them, they did not want health professionals to adopt a blanket approach to treating all Black people the same. They, however recognised that for many in their communities, culture and traditional religious practices were an important part of their identity. He said:

> Even though we haven't abandoned our cultural roots we recognise how less traditional we are, and that culture doesn't feature in our everyday decision-making. (E5: 40 - 69 years)

There was a discussion about the importance of participants connecting with health professionals and how it was important for some because they saw the benefits of getting health professionals getting some religious insight could form part of the missing health prevention information. One woman talked about misconceptions about the practices of various religions and that there could be learning from each other:

> I remember talking to a health professional about my diet because I am diabetic, I told her that I was fasting, she said, she didn't realise that I fasted and thought it was something that the Asian communities did. I need practitioners to understand me if anything is going to change. (F6: 40 - 69 years)

One of the women who attends the church for social activities spoke about the activities that took place in the church building where we were holding the focus groups. She referred to the health prevention leaflets that spoke about different forms of exercise including yoga and different types of meditation. She highlighted that one of the things that is insensitive and goes against some religious practices are various forms of yoga:

She said:

> You know, things like yoga, reiki and acupuncture is not allowed here in the church, you cannot say you are a Christian and practice those things. (F6: 40 - 69 years)

Awareness and understanding of differences in religious beliefs and cultural values is necessary so that people are treated with religious and cultural sensitivity. Overall, this theme highlights the impact that limited practitioner understanding can have on the engagement of the communities.

4.5 Summary

In summary, the findings from phase 1 of the study highlight some key concerns for people in the Caribbean and African communities in Greater Manchester. The overarching themes from this phase include Encounters with Health Prevention Information; Obstacles to health Engagement and the Significance of Faith and Culture in Decisions. The findings demonstrate how public health information relating to CVD is understood and enacted upon through their experiences. The findings highlight the need to understand the experiences of participants from phase 1 further. In the next chapter, I present the findings from 6 participants selected from phase 1 to provide further depth and discussion surrounding their experiences of health and their health outcomes.

Chapter 5

PHASE 2 – FINDINGS

5.1 Introduction to the Chapter

This chapter presents an overview of the findings from the focus groups in phase 2 with N=6 participants over a 6-week period. All six participants had taken part in phase 1 of the study that was conducted with a total of N=120 people over a 4-week consultation period. During phase 1, I developed an understanding of the factors that impacted upon participants' awareness of and responses to a selection of publicly available public health prevention information. Phase 2 was conducted for 4 weeks following phase 1 and took place between August 2016 and October 2016. The six participants whose profiles and backgrounds are outlined in the methods section of chapter 3 are represented by pseudonyms when presenting the excerpts from their conversations in this chapter (see table 5 below). I have referenced these participants differently from previous findings chapters because I wanted to format their comments as conversations to reflect the more intimate nature of the some of the exchanges we had with each other. Throughout this chapter, I will characterise the subthemes using verbatim quotes from the participants. I chose these quotes to represent these subthemes from my cross thematic analyses of the data where I had already grouped participant data into subthemes. These quotes stood out to me as being emblematic of the data groups that I had already assembled.

Phase 2 – Participants demographical data

Pseudonym name	Gender	Place of Birth	Age	Geographical location	Profession	Religion
Samuel	Male	West Africa	40 - 50	South Manchester	Business Man	Non-practising
Leon	Male	England	40 - 50	South Manchester	Religious Minister & organisational Chair	Christian
Arley	Male	Jamaica	50 - 60	Central Manchester	Student/photographer	Catholic
Blessing	Female	West Africa	50 – 60	West Manchester	Pharmacist, Minister and Organisational lead	Christian
Femi	Female	West Africa	60 - 70	North Manchester	Homemaker	Christian
Mona	Female	England	40 - 50	Central Manchester	Council worker	Non-identified

Table 5 – Phase 2 Participants demographical details

Phase 2 answers two research questions which gives guidance to the study.

- Research question 2: What do the voices of Caribbean and African people tell us about their health experience and its influence on health outcomes?

- Research question 3: What are the perceived (from a communities' perspective) professional health care behaviours and attitudes that produce poorer experiences for Black People?

In chapter 3, I presented the analytical process I went through to arrive at the themes that were developed from phases 1 and 2. This included data analysis with the participants at the end of phase 1 and 2. Once I had collected all of the data from each phase and themes were developed, I identified commonalities across each of the thematic areas. During the analysis of phase 2 data, I followed the same process I undertook for phase 1. Once the data analysis was complete, I spent time mapping the themes from phase 1 to ascertain whether there were any commonalities. The findings of this first phase were used to guide data collection in phase two; data from phase two was analysed in the second cycle of data analysis.

What I found during this process were similarities that were cross referenced between the phases. Three wide-ranging overarching themes were identified throughout the analytical process in phase 2 and captures and develops themes from phase 1 of the study (see table 6 below). This is the relationship between phase 1 and phase 2.

- Phase 2's 'Significant Influences on Individuals' theme was developed from the 'Significance of Faith and Culture in Decisions' theme from phase 1.
- Phase 2's 'Discrimination' theme emerged from the 'Obstacles to health Engagement' theme from phase 1
- Phase 2's 'Black Health' emerged from the 'Encounters with Health Prevention Information' theme from phase 1

Significant Influences on Individuals	Discrimination	Mirror of Black Health
"This is how I cope" "The Shame and Stigma of Disease" "Our Own Internal Matters"	"It's never about meeting our specific needs" "They do not value us enough to invest" "We are just plodding on through the issues"	"Consequences of being Black" "It happened to me, my mum and her mum"
Significance of faith and Culture in Health Decisions	**Obstacles to Health Engagement**	**Encounters with Health Prevention Information**
"My culture and faith counts" "I need practitioners to understand me"	"Help us make sense of health information" "There are certain ways we do and say things" "Generational Differences"	Feeling Ignored" "We are here but where are you""

Table 6: Themes Phase 1 and 2

5.2 Overarching Theme 1 – Significant Influences on Individuals

The overarching data in this theme reports on those significant aspects that influence the lived experience of the participants and the impact upon their health. For all participants, faith, beliefs, religion and spirituality played some part in their lives and helped to shape their responses to how they make decisions. This theme includes the ways in which the participants experienced health challenges, their responses to coping and the other factors that impacted upon the individuals about diagnosis and the different reactions people in the communities had towards each other. This theme provides a deep analysis discussing the nature of participants' affiliation to their faith, culture and support networks.

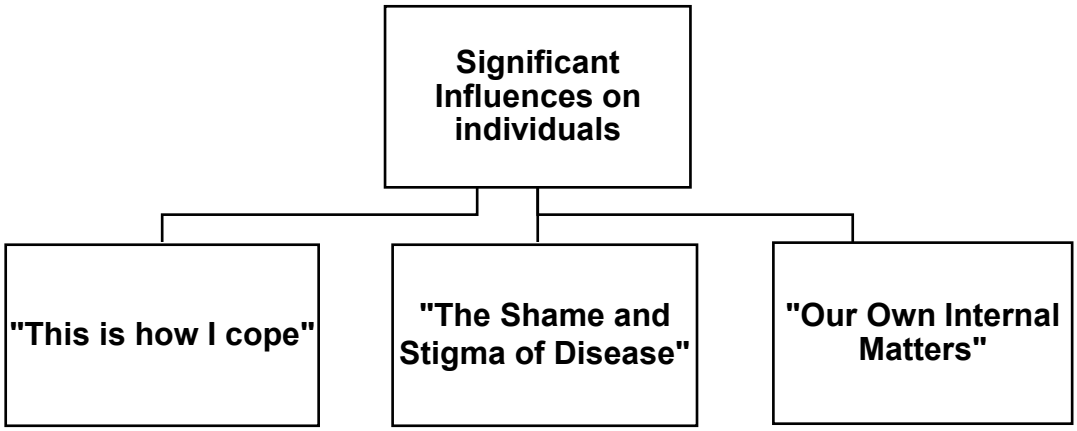

Diagram 7 – Phase 2 Overarching theme and subthemes 1

5.2.1 Subtheme 1: "This is how I cope"

From the group conversations, coping was a key feature of this theme. It was apparent that religious and cultural beliefs influenced the lives of the participants and helped them to cope with the daily challenges many of them faced. All participants spoke about their responses to coping and some spoke about how faith and cultural practices influenced and principally shaped how they reacted to many setbacks. Some participants expressed that being able to rely on their faith was the most important mechanism to cope with health challenges and discriminatory practices although some saw faith as problematic. Participants

stated that some of these challenges and judgements came from within their own communities which would often lead to divided communities.

Applying phase 1's checking-in activity[25] that involved participants eating Caribbean and African foods together, I wanted to know whether there was anything symbolic….

> Arley: [Almost choking on his chicken bone, others laughed] ……there is something about having a plate of this kind of food. It is cultural food we have in common; it is a way of putting to one side issues of the day and really nothing else matters at that time.

This was completely acknowledged by the others in the group that talked about the ability to relax and be with people like them. Samuel, one the community leaders of an African organisation stated:

> Samuel: Cultural practices... I would say that this was and is incredibly important to me as when I was growing up in West Africa and even more since I migrated here, I have never changed my cultural ways of doing things because my culture is what gives me a sense of identity and feeling of 'home'. If I did not have my cultural ties, then I do not know what I would do because I live in an area where people do not look like me.

Although two of the participants discussed the importance of culture and the way they did things when they were growing up, they said that being together and spending time together was a cultural thing that helped them to get through some really hard times especially when they were new to this country.

> Mona: When I was young, all around me was cultural practices that I do not really recognise today. Whether it was the food, the family that came round, at our house it really was about the village that raised the child, no-body would get away with anythin', there was always someone that mum knew that would ketch you doin' something.[26]

Leon a church pastor and community organisational-lead added to Mona's experiences and shared how important it was for him to hold onto the cultural

[25] This is an extension of Significance of Faith and Culture in Decisions overarching theme from phase 1

[26] In the Caribbean dialect means that no one would get away with anything without being caught by someone known to the family

practices, which led to an extension of his family. He agreed with Mona and said we have lost a lot of that now:

> Leon: As a father of three, keeping hold of those aspects of my life I experienced when growing up is incredibly important. For me, I don't just view my blood family as family but my church family too this is where I get so much support to help me get through some of the challenges, I face.

Arley expressed the importance of cultural practices that keep people together and feeling supported especially when faced with some of the structural challenges Black people experience. He spoke about the time when he migrated to this country from the Caribbean and how his family kept hold of the cultural practices. The following quote from him exemplified the point and the importance of cultural coping tools when he arrived in the UK

> Arley: For me, migration to the UK was such a big ting when leaving sunny sunny Jamaica. No matter how excited I was when leaving and I was only 7 when I left, I just noticed more than anything the White people everywhere. Coming from a place where most are Black and then this; and to face the level of discrimination, having your family and church people during dem times[27] was important when trying to get on in life. The amount of times I would get stopped by the police was unreal, every time it happened mum would call on a church elder and the praying that took place was surreal man, I never understood it then, but they were praying for me to stay strong because they knew what I was up against.

Although Mona was brought up in a Christian and religious household, she turned away from her religion because she did not follow much of the teachings. As in phase 1, she wanted to say that she didn't necessarily use her religion to cope but more her cultural beliefs and practices. Mona was keen to emphasise that not everyone within the Caribbean and African Diaspora communities attributed the same level of importance to religion and The Church community that Leon spoke about.

> Mona: Its interesting hearing a lot of what you are saying, I used to hear my mum talking like this which was all about God and being guided by him. I'm not sure whether Black people really believe all of the Bible and all that, I personally think it's a way people used to cope cause I used to be like that until I woke up. Everyone can believe what they want but I just struggle with how some will not hear or listen to

[27] Dem means 'them' in Jamaican dialect

> anything else unless it's in the bible. To me it is enslavement and its oppressive and it still goes on today. It's a distraction from what we really need to be focusing on as Black people.

In contrast to some of the Church-experiences of health seeking already shared, some faith leaders such as those from the Pentecostal tradition, are deemed to be instrumental in motivating others in church congregations to take more responsibility for their health. This came out strongly in phase 1 and identified how people coped. Leon wanted to share some important biblical guidance that he often used that was key in the lives of many Black people to help them to cope through health challenges. He went on to quote this popular scripture reading because he wanted to highlight the importance of faith when it came to health and healing. Leon read:

> Is anyone among you sick? Let them call the elders of the church to pray over them and anoint them with oil in the name of the Lord. And the prayer offered in faith will make the sick person well; the Lord will raise them up. If they have sinned, they will be forgiven. (James 5:14-15, New International Version).

Leon was sharing aspects of his own life and the way that he led his church. He spoke about the importance of his church practices not doing what the mainstream does by imposing ways of doing things on service users and patients. He was keen to talk about involvement of his congregants in the different and responsible roles within the church and saw this as improving wellbeing.

> Leon: Church leaders should 'lead' and should ask what the concerns and views of their congregants are rather than imposing interventions upon them [congregants] which is what we see out there in mainstream services.

Some participants acknowledged the slow changes happening especially in the Pentecostal churches where many of the leaders would take full control over people's lives and what happened in the church activities. Arley who left the Pentecostal church some time ago said it was one of the things that the Black church has started to change but did not do before.

> Arley: It [Black-led church] was very hierarchical in the church that I went to before I moved to the CoE. Nobody got a look in other than the

> leaders, for me, I battled with all of that at the last place. I wanted the church to be my sanctuary, not a place where there were people trying to control others.
>
> Blessing: I do agree, the church is supposed to be a place of support; members need to have a degree of control, it is like a form of recognition of them as people by ensuring they are involved. We would often encourage people to take a lead in certain activities, some do not get those opportunities out there and I know that before I came to this church, I had never been given the opportunity to speak to a room full of people. It has helped me in my work.

Blessing who is a West African pastor and a community organisational leader spoke about the importance of being with people that are sympathetic because the way that things are done in the UK are very different to being at home.

> Blessing: There is just something about being with people that you can affiliate too, there are so many of us here that meet regularly and share especially how to support each other with the challenges like immigration, we discuss general health topics because the offer here is so different to that we have back home. Many of the churches that we belong to here in this country were formed back in West Africa and we normally attract people that we have some affiliation to back home. Although no-one is excluded, people tend to go to where they feel comfortable, we see this in the Caribbean church too where people from particular islands will worship and socialise together.

Overall, two of the participants that attended church did not believe that all Black people that were diagnosed within mainstream services were really suffering with mental health. They believed that they were misdiagnosed as having mental health problems because of how they communicated with God.

> Femi: People here do not really understand how we as Black people express ourselves and deal with our challenges, they just do not get how sometimes in church and [home] and when we are out and about doing our daily business we speak to God and sometimes in tongues, these are our religious expressions and they [western health professionals] call it mental health disease.

This experience shared by Femi provides some insight into a lack of understanding by health professionals of the significant role religion plays in the lives of many Black people.[28] Having strong faith is often a coping strategy to help people through challenges but can be often misunderstood as mental health illness. This

[28] This is an explicit extension of the phase 1 subtheme "I need practitioners to understand me"

only serves to disengage Black people from mainstream services when services do not value their culture or religious practices.

> Femi spoke about her unlikelihood to access services because she derived more comfort and confidence in her cultural and religious beliefs as a way of coping. She described her faith as being so strong:
>
> Femi: Every day when I wake up in the morning I pray and have faith that God will take me through the often-stressful challenges of the day, when I say stressful these may be financial. When I was back in Africa 30 years ago, we did not have doctors like here [UK] we had traditional healers, they were sent as doctors and we believed that God would use these people to protect us from getting mentally ill.

The participants then started to share incidents of micro-aggressions towards them, where people would casually treat them with suspicion and distrust. These events will be discussed again later in the context of the chronic stressors that can cause ill-health for Black people, intergenerationally (see chapter 6).

Femi shared something that happened at her work a few months ago that raised a question about others' perception of her Blackness. She said for the first time her being a Black woman blatantly hit her and had such an impact on her ability to develop relationships with other staff members.

> Femi: I had the most awful day that I will remember for a long time. I work in a large open plan office and there I am the only Black person and I do not have any relationships of note with the other staff in the office. Normally, I just go in, do my work and leave but that day I decided to work a bit longer. The next day when I arrived at work, we had a team meeting and one of my colleagues mentioned that a book had been removed from her desk and asked that the person return it. In the years that I had worked there I never had so many eyes on me, I felt accused and clearly in my view I was not guilty of anything. I just prayed and said God, please let somebody return that book. Thankfully, the book was delivered back to the person by another colleague. This was awful, I really just wanted to get up and walk out there and shout how racist they all were…ahh….

Arley wanted to make it clear that for him these kinds of things happened to him all the time. He spoke about how people were generally suspicious and questioning and that it was just something he lived with, especially in his younger days.

> Arley: Teachers, police, shops wherever you went it was like White people were on edge about what you were going to do next.

Mona commented that Black people themselves are also to blame because we expect each other to be strong and cope with whatever we are subjected to. She spoke about the long physically demanding days topped off by the discrimination and how tolerant, almost accepting and silent we are about these experiences.

> Mona: Managing all this on a daily basis is too much, it is toxic and Black people cannot adjust. You get the subtle racism and discrimination whether it is in the school, the health centre or at work and it is all too much.
>
> Mona: I personally believe that we Black women have really embraced the idea of the "strong Black woman" and I am talking about myself here too. Our mothers our aunties and all taught us to do this and not to complain. We are so good at pretending that everything is OK so much that we suffer in silence, it is this that causes us to become really ill.

For example, Mona shared how her mother would respond when she would come home from school crying about how she was treated [racist name calling and being singled out negatively by the teachers in a white majority school] in school. Mona said she was told she had to just shut up and get on with it and how her mum just told her that it was life. Femi came into the conversation and said:

> Femi: Our mental health is suffering because we stay quiet, we can go to church on Sunday morning, clap and sing but really deep down we are hurting from the challenges we face whether it is about being told we are just not good enough.

Two of the participants spoke about their diagnosis but refused to take the prescribed medications for it because they believed that their diagnosis could be managed by reducing some of the stressors themselves.

> Mona: I refuse to take them, the best thing that can happen to me is for these people like the school stop giving me so much stress, I battle with them and my son every school day, they think they can talk to me anyhow.
>
> Femi: When you look at all of this it's easy to understand what's going on with our health and so many of us miscarry including myself.

Mona spoke about how much she leaned towards her community for support but also stated that it was also challenging to get support every time it was required because she relied on those who were also struggling with work and other things. She spent some time reflecting on how she was never able to take any of her four children abroad or enjoy a relaxing holiday in this country because if she doesn't

work then she didn't get paid. Bringing up her children was a challenge and even with her education she was up against barriers that she started a degree programme three times and had to pull out from each one because of family demands.

> Mona: I think the stress of daily life [referring to micro-aggressions that she experiences] led me to deliver premature low birth weight babies and one with learning disabilities which has further impacted my physical health.
>
> Arley: Its crazy man, the conditions in which we live in are so bad, we end up in the worst areas to live, the lowest paid jobs and no wonder we have so many health problems with our mental health, cancers and all them sort a ting.[29]

5.2.2 Subtheme 2: "There is so much shame and stigma of disease"

This theme was developed from a range of discussions with the group which highlighted the negative association with several health conditions that would be stigmatising and bring shame to the individual from cultural and religious perspectives. Although religion, religious and cultural beliefs were expressed as facilitating the process of coping, they were also perceived by some as a barrier to supporting people with various health conditions. Participants shared some of the religious and cultural practices that were significant factors impacting on their lives and people in their communities.

Participants referred to some of their communities' members who refused to engage with some services regardless of knowing about others who had been affected by disease:

> Arley: I cannot say them [other men] and not refer to myself in this, there are some things that I will just not do despite what they [health professional] advise. That test that you have for prostate cancer, I will not let anyone near me, yes it's pride but…and I know that as a Black man I could be at higher risk of getting the cancer.

[29] Ting is thing in Jamaican dialect

> Samuel: And it is even worse when if you got a female doctor.

> Mona: That is so true, but excuse my ignorance, I know Black men are proud and all of that and think that they are somehow immune, but, I cannot get my head around why they would put their life at risk because they think they are too masculine to have a doctor examine up his backside. What are they trying to prove 'cho'…[30]

> Arley: There are just some things that you just do not do as a man or as a Black man and especially among our older men who were considered from a cultural perspective to be head of the home, strong, masculine……..

Femi could relate to what Samuel was saying and went on to say:

> Femi: Even though we say we are a close-knit community and we support each other, there are some things that we hold back with, it is cultural, admitting problems is almost like you have failed.

While many of the participants found it helpful being located within a religious and cultural space that helped them to cope with certain challenges in their life, Samuel went on to describe how the silencing and shame of some health conditions such as mental health and dementia led to people becoming isolated and not getting support they need:

> Samuel: I feel really sad at times about the state of things for us because I can see that many people we have lost through illness could have done something about it had they spoken to someone.

> Arley: I too am guilty; I am not the first to visit a doctor for anything.

The topic of mental health came up because Mona who was born in the UK and attended church until she was 18 years old was concerned about a family friend who was diagnosed with a mental health problem. She wanted to share her frustration about the unhelpful response she received when she attended a church for support about a mental health problem her friend was diagnosed with. She could not understand why the church refused to accept her friend had mental health problems and therefore offered no support. She shared that Black people were often treated badly by all services and wanted support for her friend from the church community:

[30] Cho is Jamaican slang to mean in disgust or annoyance

> Mona: I find it difficult to understand the approach taken to people with mental health problems in the church, I see it as destructive because it fails to recognise mental health as something real. This gets me so mad ….It is like we are punishing our own people.

Arley moved away from the Pentecostal tradition and now attends a Church of England. He shared how disappointed he was about some of the religious practices held within Caribbean and African Diaspora-led churches especially around certain forms of support:

> Arley: Mental health is often unrecognisable within the Black-led Christian faith…. this poses a danger to people's health. What I find somehow odd is the lack of support for people who genuinely are diagnosed with a problem, it might be mental health or cancer or something and the minister says it is of the devil. They would pray and tell the person to also pray to remove the evil.

Blessing acknowledges this tension within Church settings:

> Blessing: Although we follow the bible to guide us in our daily encounters it is not easy because we know sometimes decisions can become complicated and appear to conflict between professional advice and religious advice. It is very strange to some, but we help people to cope with things like mental health and cancer for example by praying to cast them out, it doesn't mean that people shouldn't visit the doctor as well.

Participants shared their stories about the suffering of family members and those within the church community who did not disclose their health conditions because of how it was culturally or religiously interpreted. They shared that there were so many ways in which Black communities felt stigma and shame and kept things to themselves or in a small circle.

Samuel commented:

> There are just somethings that you just don't say, it's not accepted. Dementia is another one, the number of people that do not use the D word for dementia is again that denial of the condition. They would sooner use memory loss instead of that word but then how do we engage with services if we do not use the correct or known terminology.
>
> Femi: It's true and when someone passing on, it is very rare that we disclose why they died because it can be stigmatising.
>
> Femi: There have been times when I just wanted to run away when I was so so low and lonely which was making me feel so much worse. I could not share this with my Pastor because of how mental ill-health

> was viewed as something from the devil. For me it really was a matter of life and death, I could not tell any of my friends because they would think I was evil and possessed. I didn't want to go to the GP, but I was left with no choice.
>
> Femi: to be honest there is so little compassion or empathy in our community when it comes to certain conditions, anything like HIV, or cancer or mental health is stigmatising and shameful, why? and many will just leave you to get on with it and this is whether they say they are a Christian or not."

As reflected by the participants, so powerful is the stigma and shame of some conditions in the Caribbean and African communities that it was considered by the participants as contributing to poor health for people in the community.

5.2.3 Subtheme 3: "Our own internal matters"

This theme resonates with the previous subtheme and presents some of the discussions that the participants identified as significantly influencing their daily lives. The participants gave examples of how they saw both positive internal working of the Black communities but also expressed that there was some internal disharmony in and between communities that created stressors for the community. Informal support was identified as family, friends, the communities, community organisations and church.

Overall, participants were clear that there were some very positive aspects of the African diasporan culture. Mona started to talk about the large gatherings when somebody passes and that this was a typical feature of Black Caribbean communities.

> Mona: Once you here somebady die..[31]no seriously,……. within a few hours, everybody would know about it and be there to support the family. They would turn up in their numbers at the funeral even if they didn't know the family that well.

There was a clear acknowledgement of how different communities came together to set things up to support their specific communities whilst holding on to their

[31] Sombady in Jamica dialect means someone

specific cultural beliefs and practices. There were a number of community organisations that people spoke about that were set up when people arrived in the UK. The participants spoke about how important these groups were to help people to connect with people like them and to support around issues like immigration

> Femi: In some Black communities we formed our different community networks and support groups when I migrated to the UK; just like we still have now. They were somewhere to turn for help with some of the challenges with papers and simply just how to survive here. It was important we all held onto own language and cultural ways of doing things like back home.

Femi draws out the self-help among people in the communities and wanted to see these initiatives given more attention in the communities because she was part of one and really valued what it allowed her to do when she first arrived in this country.

> Femi: Although I know it still goes on, we don't shout about these things and pass it on to our children, that is our cultural heritage being eroded right there.

> Mona: But it is not as common especially amongst Jamaicans…them were the days when mum from the top of the stairs would shout Waayne, 'a who turn fee gwan get di partnar money dis munt.[32]

> Blessing: In fact, we see that practice back in West Africa which is called susu in Ghana or Tontines in Nigeria. We use it to raise capital because here [UK] even now, the banks will not loan us money and do not see us as credit worthy. We could not be asking to borrow money from people all the time. For me, this isn't only helping myself, but also other people and it doesn't incur any interest.

> Samuel: For those that are ok it gives them the opportunity to put some away or send money back home and if people get unwell back home and need the money urgently then they may swap places, so people can receive theirs first.

There was a discussion about the importance of community, where participants spoke about how communities would generally come together to support each

[32] This is Jamaican patwa and loosely translated means "whose turn is it to get the partner money this month". 'Pardner' is a community lending system that was brought over by immigrants from the Caribbean in the 50s and 60s to assist with saving towards house purchases and the like. See chapter 6 for more details.

other especially during times of grief. However, there was also some discussion where participants expressed how within communities especially with Black organisations there was some real internal disharmony and a lack of support.

> Mona: I don't know what is wrong with us as a people, we take on such negative opinions of ourselves as Black people, we have such low expectations and when someone does something good or achieves something, we Black people are the first to try and bring them down. It is so bad.
>
> Femi: It is so true, there have been countless times when organisations have had an achievement, sometimes it can be so small but yet there are still people looking on and saying who do they think they are.
>
> Samuel: Black people behave as though you owe them something when you achieve for yourself, it's like we all need to share the success which I must say I do when I can.

Arley points to the way in which he saw Black people behaving like this in Jamaica and spoke about how it would sometimes result in people performing witchcraft to stop people being successful.

> Arley: Him badmind mi kaaz mi a dem say if mi can't have it dem dey not fi success.[33]

Mona spoke about some of the community's behaviours and attitudes that would really hurt how people viewed themselves and how this impacted upon people's emotional wellbeing. She said there was a real power struggle in some cases for recognition from other community members, she said it wasn't just about obtaining resources.

> Mona: I must admit, I used to have a bit of that nasty jealous behaviour myself, it wasn't nice when you saw people alongside you doing well and you weren't. I don't think people realise [I certainly didn't] the amount of stress all of this causes when you hear so many negative things about you in the community. I say this because we are such a small community round here and no one wants to be seen negatively.
>
> Arley: It is bad, we do have enough to deal with when them out there are racists and bringing us down never mind our own Black people, I don't care where they are from Africa, Caribbean…Bajan, small island and so on, they are Black and we all then suffer the same.

[33] Used to describe someone who is jealous of others: He is of a bad mind, If I cannot have it then they can't either.

Even though participants spoke about the challenges for them, some shared that they too or their families perpetuated some negative stereotyping ideas about Black people. Mona gave an example of this in her own family.

> Mona: I grew up in a predominantly Black area, but mum sent all of us [children] to a majority White school because she felt that we would stay out of trouble there than being with Black people.

Samuel who has worked as a community lead for a number of decades stated that funders already had views about Black communities and the inability to work together and manage their own affairs.

> I often find that when we apply for funding, we get seed corn amounts because Black people are said to have a poor reputation with managing finances and also delivering on what we said we are going to do. When we fight amongst each other they see that and do not trust we can meet the needs of our own community.

This theme provides us with some insight into the lived experiences of the participants in relation to how they coped with everyday challenges which for some meant leaning towards their faith and some towards the community with whom they felt a sense of belonging. Participants articulated the stigma and shame associated with certain conditions and how this had a significant influence on them and the wellbeing of Black people. Not all concerns were about external factors, as participants raised internal concerns that would cause stressors in their life and create internal disharmony.

5.3 Overarching Theme 2 - Discrimination

Although the group came to participate in this study as individuals with a lived experience, it was often the case that challenges shared by the some of participants involved a significant aspect of the work they did for their organisations, as many of the participants were also community and organisational leaders. The theme discusses the covert discriminatory practices that participants identified as blocking access to their own health and wellbeing.

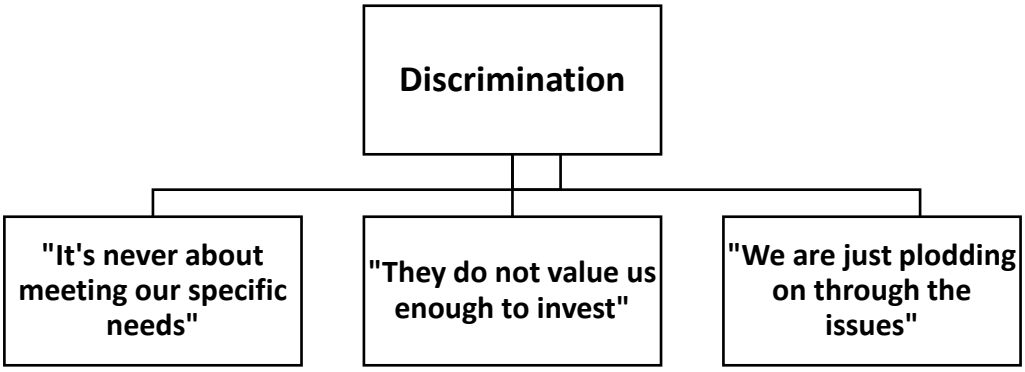

Diagram 8 – Phase 2 Overarching theme and subthemes 2

5.3.1 Subtheme 1: "It's never about meeting our specific needs"

In contrast to the daily micro-aggressions, as previously discussed by the participants, which they believe lead to chronic stressors and ill-health, this theme highlights how participants perceived the overall systemic unfair treatment by decision-makers and health care staff either as an individual or as community-led organisations. They expressed that even though their services were of often cited as valued by the communities, it was not reflected in the overall decisions that agencies made to fund their work or to address their health needs. This theme raises frustrations from the communities about the overall lack of power to change the way they are cared for in the health system.

The issue of care and how Black people are treated came up in one of the phase 1 focus group conversations. So, in phase 2, I took the opportunity to introduce the book *The Immortal Life of Henrietta Lacks* by Rebecca Skloot (2011) to continue the conversations started in phase 1. This resulted in my own deep reflection, as participants spoke about the unfair treatment they had received in health care particularly in primary care (chapter 1 and my autobiography) The book charts the true story of a poor Black woman Henrietta Lacks and highlights her mistreatment and betrayal by the medical profession, as she attended a poor charity hospital in America. The medical profession stole and sold her cancerous cervical cells to research without her consent when she was diagnosed with

cervical cancer. Mona wanted to express how the book made her feel about the persistent mistreatment and devaluation of Black people, especially Black women.

> Mona: I was handed this book some-time ago and read it and was so angry in how they portrayed Henrietta in their usual racist ways as this Black strong loose woman and mother of five who had no idea of how to look after and respect her own body. This is similar to all those other experiments when they test on us Black people like animals.

The importance of building trust was emphasised by the participants and links to phase 1's overarching theme about the Obstacles to health prevention. They spoke about how this led them to disengage with services because of past experiences and the lack of attention directed towards meeting their specific needs. Participants stated that sometimes this meant Black people would go to the health care providers late because of lack of trust.

> Femi: The Henrietta Lack's story is a classic reason why the medical profession doesn't have our trust, although this happened a long time ago, we still hear many stories about Black people being mistreated and by the time they get to the GP or hospital, symptoms have gone so bad and they don't come out well.

Subsequently, this began a conversation about representation in terms of how decisions are made regarding who gets what, Arley commented about the need for more Black people in senior roles to help change how people view health services.

> Arley: If we could identify with the people that are meant to look after us, then there may be more trust and me myself would be more likely to engage.

However, Mona did not think that representation alone would get Black people engaged and said that sometimes Black professionals themselves do a disservice towards their own people, as she hints at structural discriminatory practices She said sometimes they too look down upon Black people as though they are better than you.

> Mona: There have been countless times when I have been dealt with by Black people who treat other Black people badly, we were saying this earlier. Even worse still, they are sometimes like puppets, just bowing down to what the system tells them to do even if it isn't good for the individual [Black person].

However, Mona also shared:

> Mona: Can I just come back on that point about Black professionals. There is one GP who happens to be a partner in a practice in Old Trafford who is brilliant. She works in an area where there are lots of Black people and I remember taking my mum to an appointment with her some years ago. I must say, I did sit there huffing and puffing as my appointment was delayed by at least about 40 minutes. When I got into the room she apologised for the delay. I was a bit annoyed and d'you know what she said. She said, "I have a lot of patients that have some really complex needs and although everyone should get the same 10-minute appointment, I give them longer. If patients are not willing to wait, then I always suggest they see one of the other doctors who just give them the time they are supposed to have". I soon shut up, I really thought about this and appreciated this Black woman doctor because she had the power to make this decision and chose to give this care to her Black patients which I had never in my years come across before…wow.

Participants recognised how this was great but continued to point to the lack of priority that was directed towards them despite having high rates of vulnerabilities to various conditions which was a point referred to in phase 1 (I reflect on this participant story in appendix 12g)

Femi makes a point about screening and provides more in depth and detail about this that added to what phase 1 participants were saying about insufficient health promotion and prevention campaigns. In her commentary she recognised that screening wasn't routinely offered to anyone over the age of 40 years. She could not understand why Black men who were likely to get diagnosed younger with prostate cancer were not prioritised.

> Femi: It is ridiculous that Black people are still not being offered screening for prostate cancer until they are 50 years old. She said, my brother who is in his mid-40's visited the GP with problems passing urine. He had been a couple of times over the last few months with the same complaint and it was only on the 3rd visit that the GP decided to offer him an examination for prostate cancer despite my brother telling the GP that my dad died early from prostate cancer.

Mona turned to Arley and reminded him about an earlier conversation about the way in which Black people tend not to engage with certain forms of screening because of the cultural shame and stigma. She wanted to know if anything would make men more likely to overcome the taboos about anal examinations

> Mona: So, if they provided that then Arley would you have gone given what you said before about not wanting to get these sorts of tests.

Arley wanted to make a couple of points about education from health professionals and individual responsibility.

> Arley: I believe the health service professionals have a duty to educate us properly about health prevention. The problem we have is that we are not fully educated about these things, because we don't really understand some of the implications, and I am going to be honest and say that sometimes we hide behind our religion and culture to justify not engaging.

Leon shared a case of what he described as direct neglect and de-prioritisation of a Black women's needs. This woman had been wrongly discharged from hospital after having her baby 2 days before. She had sickle cell, was complaining of pain and clearly unable to cope. There was, however some issues relating to lack of trust from the mother because her condition was not fully understood by the midwives and therefore had not been cared for well whilst in hospital.

> Leon: Ten days later mum started having pains rang the hospital several times only to find out she was haemorrhaging and needed a blood transfusion. The sad thing here is that even though they knew she had sickle before arrival, they could not get the blood match, we then lost a mother.
>
> Leon: We often live with real life scenarios when they cannot match the blood and we as a people whether innately or subliminally in the back of our mind do not necessarily trust the system in the sense of are you directly going to benefit from it. Are our people going to directly benefit from it, are you giving blood are you taking blood, they had scares in the past even with the haemophiliacs whereby they had the AIDs. So we are very protective in that sense and very self-preserving in the sense that we are very conscious of do I give my organs and again, there is a religious aspect in some people's minds that you need to go to the grave complete with all organs and such forth.

On several occasions, Blessing brought up the issue of being assertive and clear about health needs:

> Blessing: Sometimes, we sit there so quiet and then leave with the wrong thing or nothing. For me, and although I know it is hard for some especially if you can't express yourself, we need to be a bit more demanding or even get someone to go with you when you visit doctors and all that.

In terms of implicit bias, Blessing went on to say:

> Blessing: You see, I am not sure whether it is conscious or unconscious the behaviours, I think we need to be doing more to challenge if it is conscious because we deserve much more than that.
>
> Samuel: Yes but how do you challenge, it is so covert, and it ends up being your word against theirs and we often loose out because we are not seen by the system to be trustworthy in many cases.

5.3.2 Subtheme 2: "They do not value us enough to invest"

This theme crosses over from "It is never about meeting our specific needs" in the previous theme but presents a slightly different frustration that participants had towards the lack of investment from the commissioners into Black-led community organisations.

Femi was concerned that there was a lack of value accredited to Black-led community organisations, she said:

> Femi: In all of the years [20 years plus] that I have been working in Manchester I have not seen a contract of any decent amount be invested in a Black-led organisation, it is as though they do not believe we can get the job done.

One of the participants re-iterated what was said earlier about organisations stating that they were delivering for Black people but were not really directing their funds towards the Black communities:

> Arley: Actually there is an organisation that gets funding and is Black-led however, although it states that it addresses needs for Black people, when you look at the things they do, they never seem to focus any attention towards our Black communities.
>
> Leon: Well it is a shame for our communities really because those kinds of organisations just chase the money and deliver what the commissioners want them to deliver which means that they continue to omit meeting the needs of Black people.
>
> Arley: It is true because the allocation of that resource doesn't actually go to meet Black people's needs, actually, it ticks the box for funders and they then say that they have provided the resource.

Leon who runs a charitable organisation spoke about the numbers of people with a common inherited disorder. He was very frustrated that even though the

condition was the most inherited genetic disorder in the UK, he could not understand why in terms of allocation of resources, there was far more attention given to Cystic Fibrosis. In his experience, he shared that this was representative of the sector in general where Black people are particularly affected.

> Leon: As someone who runs a charity where people affected are majority from Afro-Caribbean communities, it is quite evident that the priority for funding is directed at conditions that in the main affect White people. It is a constant struggle every day trying to get the funding from the public purse to support the work that I am doing.

Participants overwhelmingly agreed and gave examples of some of the barriers that they too had experienced regarding access to funding to provide their services they knew were needed in the communities.

> Leon: There is something about how they commission services that completely overlooks the work we do.
>
> Samuel: It is so tiring, however, I must admit though, if you manage to get a funder that just understands where you are coming from and where you want to go he can support and consider you, the problem is when that person leaves the system is back up against you.

Linking to conversations around self-help (i.e. “pardner” and susu community savings systems) from the earlier “Our own internal matters” subtheme, Femi went on to discuss how we should be looking to raise our own funding to support our own services.

Mona said:

> There is not a single decent size Black owned business with its own premises in Manchester which is a shame, and plus we don’t even support each other to make that happen, we would rather fight each other just like when we tried to raise funds for …..to purchase …..in Manchester.”
>
> Arley: When we first come to this country, it was not the case that I could just go to a bank and borrow money, the pardner is what helped many of us to buy own homes.
>
> Femi: For me it is frustrating because we should have our own building and services to deliver some activities that will help our people, we are still heavily reliant on little funding and handouts.
>
> Samuel: Well, you hear this a lot, of course it would be great to have access to own buildings and all that but they [decision-makers] do not value us enough to invest. In all of this we must remember our starting point here in this country we never really came here with anything, we

> have always worked for the system and not for ourselves and most of this is in low paid work because that is all we could get.
>
> Leon: It is true, how can you fend for yourself when you are always kept at arm's length by the system, they block you everywhere you turn. We are not going with a begging bowl because we are lazy, we work incredibly hard, but the system is so against us and keeping us at the bottom.

Bringing the conversation back to targeted health promotions, Blessings made reference to the discussions we had in phase 1 where the communities were talking about using our own professionals to develop our own services. Although one woman spoke about working with the health services, these discussions wanted to stress that no matter how challenging, there was a need to invest in tailored materials and services for our communities

> Blessing: It is a constant battle to try and get things done in a way that could make a long-standing difference to our communities. When we spoke about all the health problems we had during the consultations a few weeks ago, we talked about how we needed to develop our own services and have our own materials that could improve things for our people. For example, we spoke about the traditional food wheel that would help and other things like that, we just need to get on with things because they aren't going to invest and do these things for us.

5.3.3 Subtheme 3: "We are plodding on through against barriers"

This sub theme came through very strongly because participants spent a lot of time sharing their experiences of knock-backs from funders. They highlighted the challenges and barriers that Black people said prevented them from building up the capability to act independently of the system and to make their own choices that would improve their health experiences. What participants did draw on in their conversations were examples of how they built up small ways to build social, health and financial capital to produce agency in their communities.

Participants in this study told stories about the way their organisations function that was not sustainable because of the way they were funded. Both Leon and Samuel stated that they were so passionate about the service that they offered and the need

to continue offering support to clients. There were real challenges because of the seed corn funding they received from organisations that caused them to lose focus in different ways, on their key objectives.

> Leon: The situation for us here is very disheartening and tiring, I say that because the health service, I mean the people that make the decisions [say the commissioners] do not seem to recognise the vast health needs of Black people. We come from a very low base, we have so many health issues …we do not really have much [money] and it is often the case that we spend so much time constantly putting in funding applications for small pots of money that only last for a few months. This cannot sustain us to provide the service that our people need.

In fact, all participants agreed with this and shared similar frustrations not only in their organisational work but in their life in general. Arley commented on the communities, overall, in terms of financial resources and said:

> Arley: Although it isn't all about money, it is very difficult to do things when there was very little money in our communities.

He went on to talk about a group that he attends that support people that care for service users with dementia.

> Arley: You go there on a Thursday and you see the people dem[34] sitting and talking about some of the struggles……. they get a few pence and when a little contribution is asked for the people them can't give because they don't have it to give.

This was an interesting point that was raised here, which recognises the limited financial capital we have in our communities that denies opportunities to Black people and prevents them from taking control and providing the care that is needed. Participants expressed through their experiences how the system dictates to Black people about how much resources are allocated and sets the criteria to which people should operate.

> Mona: You see, they have us 'over a barrel' so to speak, they know we need some specific care needs [like my child who is autistic] provided in a particular way but yet they can deny us access to decent money and we cannot do anything about it because we do not have the money, the buildings, and sometimes the right people to deliver all aspects of a service, we can't just walk away.

[34] Dem is them in the Caribbean dialect

However, Femi went on to remind other the participants that despite the limited money in the communities, people were able to use their skills and expertise to help deliver all kinds of support which was a good for Black people. Femi highlighted this, as some of the participants did in phase 1

> Femi: Money can help but many of us can develop and improve things for ourselves with very little, as a community we need to come together and start somewhere.

Blessing said we have a system set up where Black people offer a service after church and it is well used.

> Blessing: In a way and you see, Black people want to have enough to be able to manage their own business, we are not one to go shouting about not having, in many ways we see that God will provide. In our church, we deliver so much around health for example, after church, and about once a month, we have a second opinion clinic which has a pharmacist, a doctor a midwife and other health and social care professionals running the clinic. These people would be sat at desks and see the members [or anyone even from outside the church] privately to answer any questions.

Although the sources of support were small and often under resourced, participants spoke about the value that some of these support organisations brought to the communities. Within the group, some of the participants identified that their own community support groups were developed out of lived experience and out of frustration because mainstream services were not providing the support needed to meet the needs of Caribbean and African people.

The participants highlighted the value of these services but at the same time recognised how quickly they came together but also how quickly they folded due to the lack of resources invested by funders.

Femi spoke about the time when she required support for a personal problem.

> Femi: To be honest I was so grateful for the support I received when I was going through a very serious personal issue that took my partner to court and sentenced, I could not have done this without the support of my own communities.
>
> Femi: It is good that we are just plodding on through, against the issues. The support provided by people that look like me was really important when I was going through the trauma of abuse from my family back in Africa, the support was really helpful because the people that were supporting me understood some of the cultural issues about

reporting and I could not have shared what I shared with a White Social service-led organisation from the council.

Participants spoke about the level of discrimination they experienced as they tried to access care and or support to deliver on some of the gaps unfilled by mainstream health providers. Overall, participants voiced a lack of value towards them as Black people and how they were viewed by providers and commissioners. This was evidenced in the lack of investment in Black-led organisations and the lack of specific attention given towards meeting their needs.

5.4 Overarching Theme 3: Mirror of Black Health

Participants saw reflections of themselves as mirror images of their parents in relation to their health. This overarching theme was particularly key in that it provided a deeper understanding of the lived experienced of Caribbean and African people and the factors that influenced and often resulted in poor health. Some of the challenges that people faced were not solely a result of how they responded to the struggles within mainstream society but also due to what they saw as the historical foundation for the cultural practices and beliefs that led them to behave ways which I will draw out in the next chapter.

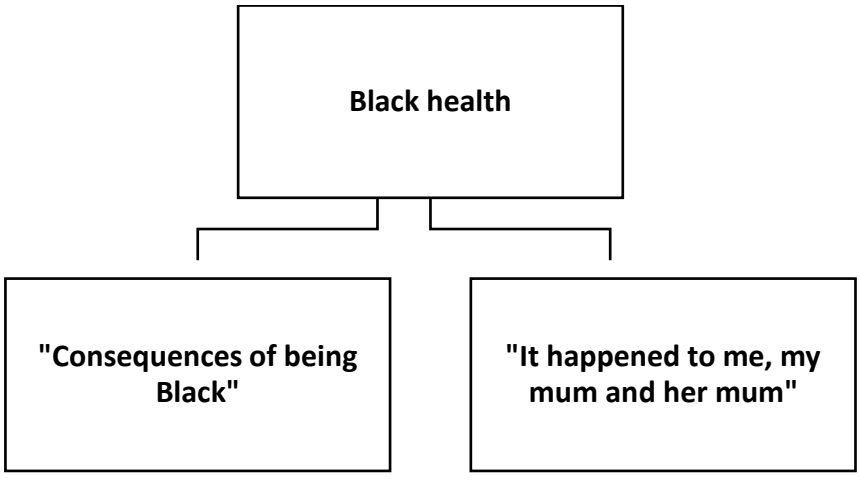

Diagram 9 – Phase 2 Overarching theme and subthemes 3

5.4.1 Subtheme 1: “Consequences of being Black”

This subtheme was categorised by the group as one of the most evident aspects of their struggle due to the lack of value being placed upon them as Black people. The theme highlights how the group saw being Black was a problem in this country because they did not have the access to the resources and cultural behaviours to improve their overall health and wellbeing.

During our second session, I asked the group to provide me with a typical 7-day food diary because I wanted to see what participants ate in a week to establish healthy eating. What I learnt from this activity was how varied each person’s dietary intake was but commonly how little fruit and vegetables people had on their plate. When I dug a bit deeper the participants from West Africa [although aspects of this applied in the Caribbean] gave some cultural reasons behind why they ate as they did.

Participants gave accounts of the impact of culture on health decisions about African woman. As the group was a mixed group of people from across different Caribbean and African countries, there were narratives about the cultural dietary and physical variations within those countries. The group spoke about several factors that came into play when determining decisions about healthy eating options. There were some traditions that influenced how they approached eating and views of being of the larger size.

Samuel shared a practice in West Africa (and one that continues here in the UK) that provides a good insight into the way food is valued

> Samuel: In West Africa a lot of food on the table indicated wealth; it didn’t even matter too much about what was on the table, it [the table] just needed to be full and in most cases it consisted of mostly carbohydrates like bread.

In the Caribbean and Africa but especially so in West Africa, there is a significant cultural and economic relationship between being overweight, being seen to be wealthy and how women are defined as attractive.

> Samuel: African women of the larger size and overweight were viewed as much more desirable.

Samuel and Blessing both from West Africa shared a cultural practice from their home country where the larger women symbolised status and wealth.

> Blessing: So, there is a fattening room when a woman is preparing for marriage and it is with a particular tribe called the Calabar tribe. They put the woman in a room and leave her there with a particular diet so that on her marriage day, she is really rounded and desirable by her husband. The natural diet for the fattening room contains a particular type of soup and food like cassava porridge where the women is just eating food that will help her to get fat and she is not doing any work at all like the tamia queen does nothing but sleep and eat and get fattened.

This cultural practice led to a conversation whereby those born here questioned why people would do that when it could cause all kinds of health problems. They referred to all the discussions around health prevention information and how significant this was.

> Samuel: Where I am from [West Africa] that just did not matter as much as the respect you got when your woman looked healthy [fat] and wealthy.
>
> Blessing: Being big over-rides health in many cases and it is all about prestige, you get so more favour if your wife is fat.
>
> Mona: This practice can create problems for our young girls growing up here because being of the larger size here in the UK is not generally seen to be attractive and it is bad for our health. I could never encourage that practice with my own daughter. I mean, we need to address our health issues, as though things weren't bad enough.

Although Mona who has four children, did not think that the practice to fatten women was good for health reasons, she was also concerned because she said it devalued women.

> Mona: There is so much devalue attached to women especially Black women, this kind of practice only fuels that and makes Black women objects.

Blessings wanted to share some education around food and how the English climate did not meet the needs of Black people. She stated that because of the climate, Black people needed specific information needed to maintain good health and this was not readily available in the mainstream.

> Blessing; Yam is still very nutritious and green banana is full of iron. Because we have plenty of sunshine in Africa, the chemical constituents are different from when it is grown outside of the tropics…. You see what I mean. So, the ones there are really much better. So, the ones there like yam has a lot of polyphenols are very anti-cancerous and you would not get that in the yam that is grown somewhere else. They mimic tropical conditions.
>
> Mona: So that is why my mum would always ask in the shop….so where is this from, she didn't want it if it from anywhere in Europe. You see she [mum] could tell where it's from, I can't but you they [born in the tropics] can tell the difference. To me that is massive. When I send my kids to go and buy me a piece of yam, they will just get the piece that looks nice, they would not know that it matters where it is from…." When my mum used to say…'where you get dat rubbish piece a yam from'?

In the group there was a discussion about how being Black needed different advice and guidance because they believed for some reason Black bodies responded differently to that of White peoples. They spoke about things like salt and how we have more heart problems because of salt consumption. However, the participants recognised that health education messages were not was adapted towards Black people.

> Mona: You see, the daily recommended salt amount is 6g but yet, everybody well certainly health professionals know Black people cannot tolerate salt in the same way so why is it that we are told to have less?

Arley came in at this point to support what Mona was saying and continued to share why people did not like to take western medications and engage in other forms of health care

> I am a little sceptical about getting involved in all sorts of tings because what may work for White might not work for Black. I mean, why is it that we have so many health problems compared to other groups, there must be something different going on that makes us respond differently.
>
> Blessing: So, for us [Black people] in terms of things like CVD, what we need to appreciate is about the cultivation, the exposure to the sun we need the chemical balance that operates within the fertilisation of whatever nutrients you are getting from the soil.

There was a concern by one of the participants who talked about her engagement with a GP who could not diagnose a skin condition that she had because of her skin tone. She spoke about how this was dismissed by her GP

as nothing to be concerned and hence sent away on a number of occasions. This resulted in Femi booking a private appointment with a Nigerian Black dermatologist.

> Femi: Over the course of 6 months I visited the GP with this problem on my chest which turned out to be a fungal infection that was spreading and needed treating, they [GP} have no idea about how to look after our skin problems.
>
> Arley: Yes but this kind of thing happens all of the time, I have a lot of have small patches on my back but mi just get fed up of asking them to look pon it that mi just lef it.

Femi spoke about the ways in which Black people need specific information and products that information is not readily available. Some in the group saw it as being a disadvantage for Black people because we were not prioritised in health care decisions. This was a consequence for Black people.

> Femi: It doesn't matter what you turn up to buy or use in this country, it could be makeup, clothes and health care, so much is done in favour of White people.

Mona stated that she never knew all of this she commented:

> Mona: But that is really good education for our communities. Why is this information not out there, why are our communities being denied all of this information? When I go shopping, I do not even think about any of what you are saying. I just pick up the things I normally buy and go home and cook it. This has to play a part in the health problems we get, and no-one seems to be researching this and educating us.

5.4.2 Subtheme 2: "It happened to me, my mum and her mum"

Over the weeks there were several conversations in the group that brought to the fore the way in which experiences of chronic health conditions seem to follow a trajectory across the generations. Many stories were told about what happened to participants' mothers and fathers and their mothers and their fathers. Phase 1 highlighted several factors that caused daily stresses in people lives such as the

number of jobs people undertook to look after themselves and their families. Although this theme had links to the previous theme in terms of the state of Black health, this theme specifically alludes to the post-colonial (see chapter 6).

Arley was particularly concerned, when others were talking about the high rates of mental ill-health in Black communities in this country that were not evident back in Jamaica. He wanted to discuss the trauma (i.e. chronic aggregation of micro-aggressions discussed earlier) that people faced here that he believed was the cause of high rates of mental illness:

> Arley: There must be something about the way that people are treated here and not back home that leads people to become depressed anxious and just feel like giving up. Where I live just up the road in the heart of Moss-side you see so many men [especially Black men] walking round like mad it must be something here……...

What was apparent from the conversations was the belief that Black people got ill because of the discrimination (both personal and structural) and barriers they faced. Participants said that this was a feature throughout the different generations where family members seem to suffer the same patterns of poor health.

> Femi: It is almost as though we are born with the tendency to develop some of these health problems because so many of us have these conditions like high blood pressure.
>
> Leon: When people experience years of trauma and you can imagine, here goes….. your mum is pregnant with you, she is experiencing a lot of negative stresses, this is bound to impact upon the health of the baby. As a pastor I have counselled so many women who have found it difficult to cope, I am pleased they come to talk to me so I can support.
>
> Samuel: You see I get the issue of sickle because that is clearly an inherited disorder, but why are we getting all the high blood pressures, diabetes and so forth.
>
> Mona: That's true and with that still… and it happened to me, my mum and her mum when I ended up in hospital with pre-eclampsia and gestational diabetes, all my children seem to have reacted to the stressful conditions I endured through all my pregnancies in that they seem to get ill quite a lot.

Mona talked about her grandmother, her mother and now herself that have had the same common health problems that we see in many Black families and

especially women. She explained that there are definitely patterns where we seem to have similar experiences.

> Mona: There is something about the way we live that causes so many of us [Black people] to have these conditions such as high blood pressure, lupus and prostate cancer seem to run through the generations.

Femi spoke about a combination of different factors that led to some of the illnesses we see in Black people such as the diet and the daily struggles we faced as Black people. She spoke about her own experiences and although she managed her own stress through prayer, she admitted that the challenges did still cause some anxiety as she explained earlier

> Femi: I think it is down to a number of things that we all often experience or participate in such as our diet, the way some people react to stress and anxiety, all this suffering can get passed down to our children.
>
> Blessing: Definitely, what the mother experiences is probably the same for the unborn child. I remember one woman who I was offering counsel to telling me that every time she cried, she could feel the baby kicking.
>
> Mona: All these things have an impact upon our mental and physical health.

Femi said that she felt it was particularly bad for Black women and talked about the constant pressures that Black women face.

> Femi: Just look at the number of women in the Nigerian communities that are overweight, me included. We are expected to please our husbands and be 'big' whilst at the same time we are rejected by White society for being big and Black. In addition to this, we can't get out to do the things we know we need to do to be healthy because we have so many demands placed upon us. We of course know the stress and what it is doing to us, it makes us sick. It is unbearable, the world is so unfair.

Overall, participants were disillusioned by their experiences where they saw themselves as being victims for being Black. They articulated that some of the health challenges resulted from cultural practices and some of those practices meant that they would continue to experience poor health throughout the generations. They also highlighted that the mistreatment they experienced within

society in general caused them to be ill as they saw racism as a challenge to their own wellbeing

5.5 Summary

This chapter has provided an understanding of the lived experiences of Black participants in recognising how their lives consist of challenges both externally and internally. The findings identify that there are ways in which the participants coped and how they were viewed by society. For some they were able to remain positive because of their faith. There was a realisation through the conversations about how the external and internal stressors they faced could be creating a cycle of poor health within their communities. The next chapter theorises and unpacks the findings for further discussion.

CHAPTER 6

SYNTHESIS AND DISCUSSION

6. 1 Introduction to the Chapter

This thesis started with my personal autobiography that provided an aspect of my own lived experience. Based on this, I argued that it was important as a Black woman, mother, Christian, health professional, nurse academic and researcher that I approached this work by looking at the health of Black people through a critical lens around race and intersectionality. Critical race theory considers the social construction of knowledge which can provide ways to firstly, lift and make heard the voices of Black people, secondly, identify ways in which to capture the measures and meanings of the social construction of race and thirdly, to develop actions to address the health disparities that are identified by those voices. My literature search revealed that a number of research studies surrounding health disparities in Black communities largely focused on the biological/genetic or cultural aspects of health or the socio-economic products of race and racism. Few of the studies in my review, heard and took into account the voices of structurally discriminated against people of the African diaspora or the factors that influence how they access health as Black people in the UK. My findings contribute to a decolonial UK health praxis that uncovers the "coloniality of power" within health and looks to the grassroots African Diaspora communities for decolonial clues. By revisiting the literature and in light of my findings, there was a clear emphasised need for a praxis where decolonial theory was applied to UK health practice in community contexts and that this approach is entirely missing in UK literature. In chapters 4 and 5, I presented the data from phases 1 and 2 to highlight several themes that resonated across the findings. In this synthesis and discussion chapter, I unpack those themes with the theoretical frameworks and policy implications introduced in chapter 1 as a way of understanding the underlying structures upon which their experiences are based. I divide this chapter in two parts to mirror the theoretical and policy discussions of chapter 1. Part I will draw out from the synthesised findings, the theoretical frameworks around coloniality and critical race introduced in chapter 1, whilst Part II will discuss the synthesised findings from policy perspectives introduced in chapter 1.

I commence this chapter restating my research questions and aims of this study.

6.2 Research Aim and Questions

Aim:

This research is principally concerned with the hidden factors that influence the poor health outcomes of people of Caribbean and African Descent. The aim was therefore to examine what it is like to be a Black person accessing health care in an Urban area in Greater Manchester.

Research Questions:

Research question 1: How is public health information understood, made sense of and experienced in the lives of Caribbean and African people in this study?

Research question 2: What do the voices of Caribbean and African people tell us about their health experience and its influence on health outcomes?

Research question 3: What are the perceived (from a communities' perspective) professional health care behaviours and attitudes that produce poorer experiences for Black People?

6.3 Part I - Synthesis and Theoretical Frameworks

This section of the work introduces the theoretical frameworks underpinning the findings from phases 1 and 2.

6.4 Overarching Theme: Discrimination and Obstacles to Good Health Provision

In both phases, the participants shared a general distrust of mainstream health care provider services, which resulted in obstacles to accessing good health. Participants' descriptions about the way they had been treated within health care pointed to a lack of positive care experiences from health care providers in comparison to majority populations. This lead them to present late, be less likely to take part in medical research, be unlikely to donate organs and take medications. One example of this was explained in the phase 1 findings chapter

subtheme 2 “Help us make Sense of Health Care Information” where a participant identified her unnecessary hysterectomy and the poor aftercare she received in comparison to that given to a neighbouring White woman. Several experiences were shared by participants that stated their unwillingness and paranoia to take medications because they did not believe that providers would offer them treatment in their best interest and in a non-discriminatory way. (see chapter 5 where several participants spoke about the treatment decisions that they made due to the lack of trust that they would be treated in their best interests). In this thesis, I refer to the various legislation and policy frameworks such as the Equality Act (2010), the Health and Social Care Act (2012) that make it illegal to treat anyone unfairly on the basis of their race, however, there has been little progress translating this into practice.

This issue of mistrust can be understood from the theoretical frameworks of post colonialism (Maldonado-Torres, 2014; Grosfoguel, 2013; De Sousa Santos, 2014; Quijano, 2007; Lugones, 2010) and scientific racism (Linnaeus, 1735; Saini, 2019; Du Bois,1952, 2008; Galton,1822 -1911). In chapter 1 and throughout this thesis I outlined, via scientific racism and the prevailing postcolonial attitudes of the time, how Black people were considered inferior (Fanon, 1965) and how even further back during slavery, medical practitioners were only required to attend to Black people at the specific request of the slave owners (Harris, 1983).

As outlined in chapter 2, Marion J Sims (1813-1883) known as the ‘father of modern gynaecology’ is an example of how enslaved Black women have been treated as inferior and dehumanised through gynaecological surgical experimentation without available anaesthesia. Procedures tested on Black women to repair vesicovaginal fistula (a complication that could occur during childbirth) was ethically justified because enslaved women were property and did not have the right to consent. This practice on enslaved Black women was also justified because they were valued for reproduction in order to produce more slaves for economic reasons (Washington, 2006). This continued until the eugenics movement when they were viewed as over producing bad stock and subject to further sterilisation experimentations (Stern, 2005). This process of medical dehumanisation also continued post emancipation, where Haller (1981) describes how the US Tuskegee Syphilis experiment (also see Rusert, 2009) was one of the most shocking experiments in history. Jones (1981) writes how Black

men were denied effective treatment for syphilis so that they could carry out experiments to understand the natural progression of the disease (Gamble, 1997) This can be referenced to how my participants spoke about how they felt ignored by providers when seeking help and support for ongoing health complaints.

More recent research has shown there has been several practices that have led Black people to mistrust western medicine and mainstream health service provision (Davis, 2006; Brown, 2007; Croker, 2013). For example, in the UK and in the US, there is an over diagnosis and overuse of medication given to Black people with a mental health condition as opposed to offering talking therapies as evidenced in reports (Myrie, 2013). This mistrust in western medicine is illustrated by several experiments that show consistent over medicalisation for Black mental health patients and a history of poor treatment in research that stems back to slave trade experimentation on Black people (Boulware, 2003; Washington, 2006). In other cases, there is a lower prescription of medication with the view that Black people do not feel pain in the same way as White people (Campbell, 2012; Abdou, 2014). This lack of trust is illustrated consistently through the narratives of my participants where they were reluctant to comply with western medicines and lean towards undertaking traditional herbal remedies to try to prevent and cure health concerns. They questioned why there was a limited amount of UK research into the benefits of herbal remedies from their native countries. This is an area of research that could be explored further and is noted in my recommendations.

The legacy of these experiments and others (e.g. *The Immortal Life of Henrietta Lacks* (Skloot, 2011)) are still evident today as historical contemporary echoes (c.f. Nazroo and Karlsen, 2006; Harris, 1983) that result in for example the reluctance of Black people to participate in biomedical research studies (Katz, 2008; Yearby, 2017), as implied by my findings.

In summary for this synthesised theme, when we take a magnifying glass to the history of British colonisation, we can identify its leading role in racism, Apartheid and the commercialised enslavement of the African people (Mignolo, 2007). However, this historical legacy continues in health today as a “coloniality of power” (Quijano, 2007) where we see Black people continuing to suffer from past echoes of colonial treatment, as illustrated by their disproportionately high rates of morbidity and mortality, for example in maternity care as discussed in chapter 1.

6.4.1 Discrimination and Poor Care

Another theme I developed in the study was the belief that Black people often received poor and substandard information and care because of their race, as seen in the literature review (Nazroo, 2009; Braveman, 2015; Becares, 2012; Williams, 2010). 'Second class citizenship' was a view that was echoed by many participants in the study where they participants (as in phase 1 of the chapter 'feeling ignored') alluded to Black people having fewer rights than others. Historically, this aspect of 'second class citizenship' can be observed with Black women who were often deemed to be inferior and who were excluded from the ideal perception of a 'woman',[35] as illustrated by Sojourner Truth's 1851 speech, *Ain't I a Woman* (Truth, 1851; as transcribed by Skloot, 2011). This can be traced back to scientific and biological racism, which identified that Black women did not require the same level of health care and information as their White counterparts (Barkan,1992). For example, in chapter 1, I discuss how the colonial killing of women maps across to poor health care of women especially black women and childbirth. I outline how there are stark disparities shown in high mortality from pregnancy where black women are five times more likely to die in pregnancy or shortly afterwards from complications. Their infants are also 121% more likely to die within the first month (Knight, 2019) and in addition, Black women are 43% more likely to miscarry which can lead to future long term physical and mental ill health. Quneby (2021) highlights the long term effects of miscarriage as a marker for complications in pregnancy, pre-term birth, fetal growth restrictions and other complications. Further still Quenby, (2021) points to miscarriage as a predictor of long-term physical health problems to include cardiovascular disease and mental health problems. Despite the physical and mental toil of women who miscarry which has significant disparities for Black women there is in no targeted pre-conception education and investment in services for Black women. One of my participants in phase 2 under subtheme 'This is how I cope' spoke about the challenging pregnancy she had due to the microaggressions and stressors she faced. She spoke about how this resulted in having premature twins that nearly died.

During the study, participants also shared experiences that they had been subjected to whilst growing up in Africa, the Caribbean and in the UK. There was

[35] See chapter 1 for my discussion of "coloniality of gender" (Lugones, 2008) whereby extending the idea that colonialism is an ongoing process, as opposed to a defined historical period.

a lot of discussion that described how the cultural traditions in the Caribbean created stress contributing to common health problems. One of the participants commented that Black people were to blame because we encourage each other to be strong and cope with whatever we are subjected to, as outlined in chapter 1 page 24 (Cole, 2018). In this way, Being Black and female presents a double jeopardy. Black women are doubly disadvantaged and devalued based on their race and gender (i.e. "coloniality of gender" Lugones (2010), see chapter 1 page 22) because there is a perception of Black women that deem them to be strong, sexualised or aggressive and this extends back through history to the time of slavery (Crooks, 2019). Past attitudes towards Black women being viewed as promiscuous and highly sexualised single mothers with many children (Rosenthal, 2016), extended the view that Black people were uncivilised and deserving of being dominated in inhumane ways. Historically, these behaviours subjected many women (who were classified as 'property' to slave owners) to sexual acts with White men without consent. For many women, this impacts upon mental health, how Black women see themselves and the expectations that others have of them (Donovan, 2015). Women in the study spoke about how they were often silenced and had to change their behaviours for fear of being stereotyped and labelled. Participants reported that they had inherited a cultural past that pointed to their ability to be strong and to cope and stated that they were socialised by their parents and elders in the community in this way in order to survive. Women in the group explained that Black Caribbean culture has been influenced by their history of slavery and stated the importance of being strong and holding the family unit together.[36] In terms of being strong to hold the family unit together, one of the participants in subtheme 'this is how I cope' spent some time sharing how she was never able to take any of her four children abroad or enjoy a relaxing holiday in this country because if she didn't work then she did not get paid. Bringing up her children was a challenge and even with her education she was up against barriers. She explained that she started a degree programme three times and had to pull out from each one because of family demands. For her, the stress of daily life led her to deliver premature low birth weight babies and one with learning disabilities which has further impacted her physical health.

In phase 2 subtheme 1 "It's never about meeting our specific needs" illustrates how Black women experiences are disregarded in relation to how the system

[36] See chapter 1 for a discussion about Post Traumatic Slave Syndrome (PTSS).

treated them and their health concerns. They spoke about the standard measures used and how services and practices were undertaken with a preference made towards White women. I referred to this in chapter 1 when I spoke about colonial education (Verweijen 2020). In this study I have shared how Black women's experiences of health care was shaped by health care systems that disadvantaged them due to benchmarking of medical and health care practices. In Chapter 1, page 24 I characterised this differentiation of status through the intersectional framework of the 'matrix of domination' where Collins (1990:8) describes how the four interrelated domains (i.e. structural, disciplinary, hegemonic and interpersonal) organise power relationships in society. I also discussed how Collins (1990) argues that we cannot fully understand oppression without appreciating the ways in which privilege can create oppression. As illustrated by Sojourner Truth (1851, 2020), societal privileges offered to White women were not available to Black women and this lack of equal treatment resulted in their societal oppression and subjugation leading inevitably to lower health outcomes, then and today.

This aspect of being treated like a 'second class citizen' was also experienced by the male participants. Using multiple identities to understand their views is also very useful, here. In chapter 1, I outlined how Black men are associated with racist stereotypes of being immoral, aggressive, bad, dangerous and violent and are 'othered' just as much as Black women. I outlined how these stereotypes were used to justify the disproportionate killings and targeting of Black men by institutions such as the police and harsher sentencing by the criminal justice system compared to that received by other groups. I discussed how these racial micro-aggressions,[37] discriminations and general disregard for the Black male body impacted the overall health of Black men subjecting them to higher rates of mental ill-health and overall poor health (Jones, 2005). I also discussed how discrimination and poor care led to the prevalence and de-prioritisation of targeted prostate cancer treatment, harsher treatment in the mental health system with drugs and non-talking therapies and the lack of targeted HIV treatment. This view is reflected by the male participants in my study spoke about how they were less likely to participate in prostate cancer screening because of their need to be depicted as strong, tough and masculine men who did not subject themselves to

[37] "Racial microaggressions are brief and commonplace daily verbal, behavioural, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color" (Derald Wing 2007:271).

an invasion of their privacy (bodies) (Schröder, 2012; Pederson 2012). However, we can also view this need to display masculinity in the context of different historical and cultural contexts, multiple identities, where Black men have felt the need to fulfil positions of cultural (tribal) authority, strength and to display the perception that they were 'cool' and did not need support (see hooks, 2004)

In terms of the historical and cultural contexts, in the Caribbean and Africa, mental ill-health can be culturally homogenised as a sign of weakness or not coping (Taylor and Chatters, 2010; Mantovani, 2017). For Caribbean and African men, it often implies weakness and implying weakness means the loss of respect and masculinity amongst their peers. Although the theory of intersectionality acknowledges the intersections of Black female identities (Collins, 2000, Crenshaw, 1989), I am also interested in the multiple identities of the Black male and how they shape their health disparities. A multiple identity, racialised and gendered approach is needed to understand the social, economic and health course of black men. By taking this view, it provides a way to understand the systemic and structural barriers that limit them from taking opportunities to optimise their chance to live long, healthy lives. Werbner (2013:410) defines multiple identities as, "positive, creative, dialogical and situational" that positively add to the subject in contrast to intersectional "identities of gender or race [that] imply an essentialising definitional move on the part of the wider, dominant society that subordinates and excludes". Here, Werbner is alluding to Nash's (2008:11-12) critique of intersectionality, "[T]hat is, while intersectionality purports to describe multiple marginalisations (i.e. the spectre of the multiply-marginalized black woman that haunts intersectionality) and multiple privileges (i.e. the spectre of the (heterosexual) white man that haunts intersectionality), it neglects to describe the ways in which privilege and oppression intersect, informing each subject's experiences". My use of multiple identities in this context, implies an intersectional mix of oppression and privilege in the site of the 'Black Man'. [38]Even though societally and internally, Black men can appear to be subordinated by 'hegemonic masculinity' (viewed as being the ideal form of being a 'man' (Connell & Messerschmidt, 2005), my participants alluded that their form of subordination is not viewed in the same way as White men in society due to the racist stereotypes applied to their masculinities. What it means to be a Black man is influenced by a "matrix of domination" (Collins, 1990) that encompasses the historical, social, cultural and economic and the constraints of hegemonic masculinity within the

[38] See Chapter 7 for more discussion about the limitations of intersectionality as a framework for my study.

'matrix' have led Black men to have the poorest status across several health outcomes as they are systematically disengaged (as in, made to disengage via chronic receipt of poor care) from institutions that provide support. Using Collins' (1990) 'matrix of domination', we can see how the complex interplay of male privilege (i.e. interpersonal) and racial dehumanisation (i.e. structural, disciplinary and hegemonic, also see Curry, 2017) organises itself at both psychic (internalisation of historical shame and degradation of chattel slavery) and societal (institutional) levels.

6.4.2 Intergenerational Causes of Poor Health

Participants in subtheme 3 'Our own internal matters' highlighted that there were persistent and chronic stresses that they had experienced through lack of opportunity and bias when trying to access resources, it did not matter whether these were personal or organisational because they all had an impact upon their mental and physical health. However, as will be discussed later, the tools they used such as the personal, community and faith networks were able to shield them from some of the trauma of getting severe mental health problems.

The chronic stressors that impacted the health of Caribbean and African people in this study stemmed from social, economic and racial determinants. Participants shared how these stressors had been experienced within the education system, low paid work, the environment and the unfair treatment they or their families had received that from their perspective, had largely been a result of their race or skin colour. The accumulation of stressors endured throughout a Black individual's life often shows up as 'accelerated aging', 'premature ageing', or' biological weathering' suggesting that Black people biologically age more rapidly than White people (McEwen, 1999; Geronimus, 2006; 2010). The patterns of underlying health conditions that the participants had recognised within their own families appeared to have filtered through the generations as each generation experienced the negative aspects of racism and discrimination in their daily lives.

In order to discuss the historical facets of the "coloniality of power" that have led to this overarching theme of discrimination and poor care, postcolonial theory (also see intersectionality and CRT as methodological frameworks in chapter 3) is useful in helping us to understand the legacy of Black people's experiences of structural colonial power; both formal and informal. In this study, this framework around coloniality has been essential because it has enabled me to focus on how historical

structural inequities have developed through the practices of colonial rule and contemporary legacies.

Genetics and biological models of health[39] have often been used to explain the root causes of poor health within Black communities. However, the stressors of racism and epigenetic[40] effects are better able to explain why Black people are more at risk of higher rates of morbidity and mortality across many health conditions, including COVID-19. Recent medical reactions to COVID-19 have tried to attribute the disproportionately high rate of COVID-19 deaths from Black communities on genes that leave Black people more vulnerable to contracting the virus and dying. However, studies have argued the epigenetic case for the interaction between structural discrimination and negative health outcomes (Graff, 2014; Shackel, 2018) increasing the call to see race as a social determinant of health (see part II). There have also been epigenetic studies that have looked at the effect of stress and how it is transmitted from the mother to the foetus in the prenatal period (Weaver, 2004; Corwin, 2013). However, other studies have gone beyond that to identify the long term and intergenerational trauma of stress resulting from slavery (Jackson, 2014; DeGruy, 2005).

In summary, the participants' articulations of feeling like 'second class citizens' pointed towards the result of a combination of an underlying "coloniality of power" and matrix of domination at both personal and societal levels that to this day continue to be felt intergenerationally in families (epigenetically). Participants' voices pointed towards the stressors that create poor health and wellbeing resulting from a myriad of determinants including structural racism being cited as a core reason for their disadvantage.

6.5 Overarching Theme: Internal Community Behaviours and Attitudes

A significant number of the participants within this study raised some of the internal challenges within their communities that were deemed to be both positive and

[39] As mentioned earlier in the 'Discrimination and Obstacles to good health provision' section, see chapter 1 for a discussion about how scientific racism and polygenism theories formed the bases for biological models of health.

[40] See chapter 1 for a discussion about epigenetics where changes in organisms are caused by modification of gene expression rather than alteration of the genetic code itself (Geronimus, 2006; 2010).

negative aspects of their daily lives. A theme that I developed included the value of cooperation and the cooperative practices within our cultures that were brought to this country. For example, several of the participants [from the Caribbean] spoke about the pardner that was a popular form of partnership community savings practiced among Caribbean people, which persisted from the Caribbean in many islands when people were denied loans from the banks. This was a good example of how Black people within this community collectively created social and cultural capital[41] to enable people to achieve access to financial resources. However, participants stated that they saw an erosion of cultural capital and a decrease in cooperation (Mwakikgale, 2007) between Black people[42]. I will write more about this in part II, when I discuss policy implications.

Internalised disharmony within Black communities has permeated Black communities for decades (DeGruy, 2005; Mwakikagile, 2007; Lussana, 2010). Participants spoke about some of the damaging internal behaviours within Black communities and how fragmented it was when it came to obtaining support on an individual or community basis. In Subtheme 3: “Our own internal matters" participants spoke about acts of jealously and competition that Black people would exhibit to stop the upward mobility of groups and individuals.

To give this issue of internal community distrust some historical context, DeGruy, (2005) describes the effect of the Post Traumatic Slave Syndrome (PTSS) in Black people’s lives today, which has resulted in Black people having low expectations of themselves, their families and their communities. See chapter 1 page 25 where I discuss repressed internalised anger, low self-esteem, community disharmony, stigma, shame and the idea that Black people are of less worth (DeGruy, 2005). DeGruy (2005) describes this as the ‘Crabs in a Barrel’ syndrome, which occurs when people scramble for resources or recognition. The legacy of slavery has resulted in the ‘crabs in a barrel’ syndrome where Black people lack support for each other; there is Black on Black killing (although this is no different to the rate of White on White killing in the US which is in fact higher) and Eurocentric standards of beauty (Coates, 2015; Owusu-Kwarteng, 2017). People are

[41] Cultural capital in the sense of “closure”. Clennon (2013:110) writes “…Coleman’s (1988) important concept of ‘closure’ that is found in networks. Briefly, ‘closure’ is a set of expectations generated by the network that allows it to benefit its members in a more flexible way than the open market could”

[42] Footnote? And page number/section (in case the reader wanted to jump straight to that section now)

unsupportive of each other to the extent that they will try to prevent people from their own community from progressing as on the plantations. Lussana (2010) argues that it is like a form of internalised structural racism where individuals belonging to that community feel threatened and further reduced to feeling inferior. During slavery, the promotion of a Black person meant that they had power over other Black people whom they could no longer treat as equals. The promoted Black individual was then treated as the gatekeeper and was often deterred from promoting other Black people; this mentality meant that there was only ever a limited number of Black people in positions of power. Smith (2016) argues that the 'Crabs in a Barrel' syndrome is wrong and that African Americans do not stand in each other's way of progress because they should look at discrimination and marginalisation as the barrier to progression instead of each other. In other words, they should recognise the "coloniality of power" (Quijano, 2007) at play in their lives and aim to "decolonise the mind" (Mignolo, 2002:71). Fanon (1965:36) summarises this decolonial mindset well with, "imperialism leaves behind germs of rot which we must clinically detect and remove from our land but our minds as well".

Phase 2 participants were particularly keen to point out the internal power struggles that they experienced with members of their communities which is worth further research as the UK literature is limited in this area. For example, one of the participants spoke about the stressors they faced when other community members from within their small knit community would try to create barriers to success of their Black-led organisation. Participants also acknowledged the destructive behaviours they also used to display and talked about that feeling of jealously and not wanting others to do well for fear of being left behind which I refer to as the 'crabs in the barrel syndrome (Degruy, 2005).. At a community level, the participants' experiences showed that these forms of internalised behaviours and attitudes were destructive and would not bring about the collective change needed to dismantle wider societal structural racism. They spoke about how White mainstream society viewed Black people as fragmented and not being able to work together in a collective way, which only perpetuated White privilege and structural racism. This is an important point because Cohen (2004) reminds us that individuals with a strong network are more likely to have a more positive holistic wellbeing experience as alluded to in Pinto (2008) review of the literature on the prevalence of schizophrenia in the Black Caribbean community.

Participants shared that there was a lack of community support in many cases for people that had conditions that were viewed to be stigmatising such as HIV and mental health. Participants presented how this felt like a double whammy where they not only experienced the external and structural discrimination but also the internal stigma that was embedded within their own communities.

6.5.1 Faith, Colonial Roots and Influence on Health

Participants spoke about the importance of their faith as providing for not only their spiritual but also their social, emotional, physical and wellbeing needs (perhaps as an antidote to the 'Crabs in the Barrel' syndrome). While many of the participants found it helpful to locate themselves within religious and cultural spaces, there is a theme that I developed that explored how this self-positioning impacted on how they engaged with services because there was sometimes a conflict between their faith and the need to engage in services, such as screening.

Stigma and its link to health conditions is especially prevalent in Caribbean and African communities. In chapter 2, I highlight how stigma within Black communities has prevented individuals from coming forward to seek help, treatment and support and that some reasons were about a lack of trust. Berwald (2016) and Mantovani (2017) refer to non-engagement and amplified late presentation to general practice for treatment because of stigma and labelling associated with disease. As in this study, Adelman (2011) highlighted that participants expressed that mental health illness was a stigmatising condition in their communities and expressed that the word dementia itself was not a word to be used openly in their community. Participants, both men and women, expressed how mental health illness was a stigmatising and an unacceptable condition in their communities. When we look at how mental health has been contextualised, this has taken place within a Eurocentric research framework (methodologies, see Chapter 3) that does not take into account how Black people experience forms of discrimination (Grey, 2013; Edge, 2013).

Some studies (Abel, 2013; Kretchy, 2013) have identified the conflict that individuals face when they are told by their medical practitioner to take their medications to manage their health condition and on the other hand, there is the minister exhorting them to believe in God for their healing. The conversations

about the daily lives of the participants identified how health capital could be achieved through the churches, using congregational health professionals.

As found in this study the intersections of race and religion are often ignored (Owusu-Kwarteng, 2017). However, religion and race intersect and impact upon health outcomes for Black people and my participants across phase 1 and phase 2 spoke about how decisions about their health was guided by their faith and religious practices. Christianity has played a significant role in the Black Caribbean and African experience and Dubois (1903 as cited in Evans, 2007) refers to this when he writes about the Negro Church. However, it is important to note here, as I have done earlier in this thesis that the church I identify here, is more common in larger islands of the Caribbean such as Jamaica and Barbados, which is where the majority of my participants were from. In smaller islands, Catholicism is more common with Sunday school taking the place of the Black church for migrants. In African countries, a similar occurrence took place where missionaries would have established churches in rural villages because they had the funding or resources to do so. As the legacy of slavery is still embedded in the fabric of UK societies (c.f. DeGruy (2005), the Black church has become a formidable refuge where people are viewed as human beings and not 'othered' as racially inferior (Morris,1993; Billingsley, 2011). In the UK, over 84% of Black people are religious and or have an affiliation to a church (Census, 2011). Black people have been traditionally committed to religious practices and see it as one thing that White people cannot control or take away (Cone, 2013). See chapter 1 for more discussion about the importance of habitus in creating gatekeepers in the wider health market. Also see chapter 1 page 42 where I discuss how the Black Church attempts to make the (health) market accessible to its members, so it in itself becomes a gatekeeper to the market. I also argue how the church can be viewed as a political entity because it can be seen to be building social capital (Saegert, 2001). Finally, I highlight how Black-led churches could also play a pivotal role as partners in that they could be a dual gatekeeper for Black communities and one for the health market.[43] Dubois (2003) identified the Black Negro church as representing a freedom that Black people could call their own and one that "survived slavery" (1898:4). In the US and the UK, Black people would pool their resources together to provide that valued space they could call their own and today that space contains a significant amount of economic wealth. On that basis, religion and the church has been a mediating factor in building resilience, stability

[43] Creating their own "habitus" (Bourdieu,1977).

and strength to allow black people to overcome the various forms of oppression endured over centuries that sustain doctrines of white supremacy.

In terms of building resilience, faith leaders have been and continue to be influential in motivating others in church congregations to take more responsibility for their health (Bruce, 2017). In my study, the faith of many of the participants was so strong that they would rely only on their faith to be healed. For some, this prevented them from engaging effectively with health services. In Caribbean and African communities, participants stated that it was often the case that when people became sick they would engage the services of a traditional healer or faith leader for healing that often involved the use of herbal remedies. This point was a natural corollary of the mistrust of Western medicines, discussed earlier in the 'Discrimination and Obstacles to good health provision' section. The healer or faith healer would often be a well-respected individual or an elder that ensured that the messages they gave would be complied with and passed on throughout the generations, this could be also seen as a positive response to intergenerational trauma or Post Traumatic Slave Syndrome (PTSS). Participants also shared that they used their faith to take them safely through their traumas and that church was an insulating factor against wider discrimination and coping. The importance of spirituality as a protective and mediating factor in the life of Black people highlighted the importance of spiritual social gathering and prayer when dealing with stressful events (Taylor and Chatters, 2010, Edge, 2013).

However, the church has not always been a place where people find refuge because of stigmatising conditions where people are deemed not to have enough faith if they rely on western diagnosis and medication. Participants in Subtheme 3 "Our own internal matters" referred to how some conditions such as mental illness, diseases such as cancer and HIV were thought to be brought about by curses and the community were uncomfortable discussing them. The stigma would prevent engagement with health services to address the condition. This poses an interesting question about the extent to which the Black Church acting as its own "habitus" can become a site of decolonial agency (towards improved health outcomes for its members) considering its colonial origins.[44]

Despite the role of the church and religion have in the lives of Black people, mainstream health services have not proactively engaged with the church to

[44] The Christian Church has also historically been a form of "coloniality of power" (Grosfoguel, 2013).

deliver health prevention messages that can help to address health disparities. The Black Church can clearly be seen as a social institution in its own terms with its own 'taste making' (law making) powers of "habitus". However, it will take further discussion from a policy perspective in part II (see Policy Implications for Black-led Organisations) to examine the extent to which the Black Church can act as a gatekeeper towards the health market (i.e. what powers does it have in the health market?).

6.5.2 Gendered Stereotypes

During the focus groups, participants spoke about fattening practices in West Africa where women were secluded from society to become ready for marriage. The female body is used a way of symbolising wealth and garnering a level of respect for the man's wife to be (Gimlin, 2002). The evidence categorises women of Caribbean and African descent as one of the most overweight and obese groups in society compared to the white Caucasian population (Shoneye, 2011; Andrews, 2017). This is often put down to lifestyle factors however, as stated, cultural reasons need to be considered in obesity education provided by health professionals and an understanding about why these features in Black women are classed as desirable. It is therefore important to provide an understanding of how Black people construct the ideal of the female body which is different to that of White people and health prevention activities should not be benchmarked to only meet the needs of majority populations.

In summary for this Internal community behaviours theme, we need to view this type of apparent community dysfunction through the lens of Collins' (1990) 'matrix of domination' but this time specifically focusing on the vectors of the interpersonal and structural. If we start with these two vectors of the 'matrix' and drill deeper, we will arrive at DeGruy's (2005) Post Traumatic Slave Syndrome (PTSS) where oppression experienced by Black people during slavery and institutional racism can result in collective multigenerational trauma and grief that can manifest in these personal and collective behaviours. We can see from this study that there is a poor understanding of cultural and religious practices from health practitioners and policy makers and this could be an area for further study. There are questions around health policy and practices (secular) and how these intersect with church/religious/spiritual beliefs and practices. Participant shared internal

practices that influence health in many ways and there was a need to be some cultural sensitivity when engaging in health prevention education to differing communities.

6.6 Part II - Discussion and Policy Implications

This section of the chapter highlights the policy implications from the findings across both phases of the study

6.6.1 Overarching Theme: Policy Implications of Discrimination

Across both phases, participants expressed the ways in which the information was benchmarked to majority population groups that excluded them from engaging with interventions due to lack of relevance to them as Black people. Here, I build on the Discrimination and Poor Care synthesised theme in part I, where a feeling of being treated like 'second class citizens' was identified, several participants in the study stated that they perceived that there was a lack of appropriately tailored information. The participants felt that this indicated that there was a systemic lack of care and interest in the health and wellbeing of their communities because of their race. This lack of information can partially be explained by a lack of appropriate training of medical and health professionals that can ignore the visual differences between individuals. The mandatory curriculum often focuses on issues that affect mainstream groups or briefly browses the topics impacting on marginalised communities or leaves it out entirely. This again, asks questions about who the decision makers are that determine what goes into the curriculum and how these decisions are biased towards majority White populations. In my autoethnography, I talk about this in my own nurse training where learning both in the classroom and in practice ignored difference in skin colour and everything was modelled on the White patient.

6.6.2 Health Access

In the UK health system, it is recognised that the health experiences of Black people are poorer, they have inappropriate access to health services and a care than those of White majority populations (Szczepura, 2005; Salway, 2016 Otu, 2020). There is a plethora of evidence that identifies how difficult late stage

diagnoses are to treat across a number of conditions (Berwald, 2016; Danaie, 2014). For example, even though Black women are less likely to be diagnosed with breast cancer in England, they are more likely to be diagnosed with late stage breast cancer and die as a result (PHE, 2016). For one participant who shared their story in the focus groups, the late diagnosis resulted in a poor health outcome. In my autoethnography, I shared my own stories whilst growing up, of family friends who died at an early age because they were not listened to in that GP/patient encounter. This has resulted in a lack of trust and engagement with health practitioners.

Health care is highly valued in society and the aim is to produce improved health as an outcome (Evans, 2017). In Greater Manchester (GM) devolution has enabled a delegated transfer of power and resources from National to Local government, which covers political, fiscal and administrative responsibilities (Mackinnon, 2015). The ultimate aim of devolution in GM is to enable freedom and flexibilities from national decision-making so that they can improve health outcomes and reduce health disparities locally (Walshe, 2016). Since Devolution in 2016, Black communities have not been beneficiaries of improved health from the £6 billion awarded to GM to be spent in Health and Social care, this is an area that requires further study/examination. To date, Black people in GM still experience high rates of health inequities across a range of health measures, some of which include high deaths linked to pregnancy, high rates of heart related diseases, such as heart failure, kidney disease, stroke, diabetes, prostate cancer, mental health, HIV (GMCA, 2017) and more recently COVID-19. Nationally, the prevalence of obesity is highest among women and children of Black African descent and this is replicated within Manchester (JSNA, 2017). However, there are limited targeted intervention to address this prevalence, which is a factor for CVD.

6.6.3 Racism as a Social Determinant of Health

Participants expressed clearly that the quality of care and access varies according to race and that the wider determinants impede the ability of Black people to access the full range of health gains that is afforded to majority populations. Participants also spoke about how they felt excluded from health prevention information and interventions that were not targeted towards their community despite their risks of poor health. They spoke about racial stereotypes made suggested that Black people were unlikely to comply with health initiatives.

However, the health care system made up of people, policies and practices has not responded to address the lack of trust Black people have resulting from their own and others past experiences. Participants spoke about how Black people have not benefited from merit goods or services such as NHS services (see chapter 1 where I talk about merit goods as commodities that the public sector provides free at the point of use so that consumption does not depend primarily on the ability to pay for the good or service) that should deliver positive externalities for everyone. However, the merit goods that exist do not do enough to equally and equitably meet the direct needs of Black communities even though health care is provided free at the point of use.

Historically, health care prevention focused on a medical model to address health and illness, which resulted in the lack of attention being paid to those factors outside of biology/genetic and cultural reasons (Mantovani, 2017; Pinto, 2008). Social determinants are a significant factor in an individual's health and can impact far greater than the amount of health care the individual receives from services. In comparison to White people, Black people have unequal access to well-paid employment and are more likely to be unemployed (Demie, 2019). Black people (particularly those of Caribbean origin) are more likely to have a worse education experience and disproportionately face more school exclusions (DfE, 2019a). Black people are less likely to live in environmentally safe conditions and tend to live in overcrowded houses (Verhaeghe, 2020). There is an abundance of evidence on ethnic health disparities yet the attention in this area in terms of policy has been neglected. See chapter 1, where I discuss the extra welfarism (Eddama, 2009) and capability (Sen, 1979) approaches where these are attempts at factoring in these social determinants into the evaluative space.

As identified in this study, Black people are more likely to be subject to racism on the basis of their physical characteristics and hence are more likely to suffer chronic health conditions including experiencing poor mental health such as depression and anxiety. This is particularly problematic for Black people who have mental health problems as they are likely to suffer discrimination effects on the basis of their race and condition. Discrimination can lead to poverty and social isolation, in addition, it can negatively impact how individuals seek health care. In order to identify, anticipate, prevent, adverse outcomes, it is important for health service providers to understand racism and bias as an ethical issue that needs redress.

The role that race and racism play in health disparities has largely been ignored by public health and was not identified as a social determinant of health (i.e. only using the welfarism approach, Keynes ([1883] 2018); Robbins (1932)) until the recent Marmot Review 10 years on (Marmot, 2020) (please see appendix 17 of a discussion with Michael Marmot and the Caribbean and African Health Network (CAHN) which referred to the lack of evidence to conclude race as a social determinant of Health). As discussed in chapter 2, there is a plethora of literature that argue that cultural factors, poverty/class and or/biology are the driving forces behind health disparities (Nazroo, 2009; Braveman, 2015; Becares, 2012; Wallace, 2016). Although the literature describes the differences between groups, the findings fail to analyse the hidden factors underlying the reasons. More recently, Fenton (2020) was tasked to carry out a Government inquiry into the possible impact of ethnicity and race on COVID-19 outcomes, which could bring about a shift in policy on the health disparities agenda.

The NHS has a poor history of care given to Caribbean and African people and studies have shown low satisfaction rates that is a measure of quality (Pinder, 2016; Rabiee, 2014). As articulated in the findings chapters of this study, participants expressed that there is a crucial lack of targeted health prevention information in written and verbal form to empower them to be self-caring and self-managing of their own health as outlined in the long-term plan (NHS England, 2019). This is evident in the way that services do not actively target Black people with appropriate dietary advice to reduce the prevalence of CVD. Participants highlighted how the information is benchmarked to majority populations as highlighted in the eatwell guide focus groups in phase 1 of this study.

In the UK, the responsibility of health improvement is placed on individuals to make health care decisions that can keep them well. However, to do this, healthcare information should be accessible, universally proportionate (Marmot, 2010) and provide care and information that is inclusive to meet health and wellbeing needs. Yet, despite a free NHS developed on the principle of equity there are significant inequitable and unjust experiences in access to appropriate care for the Caribbean and African community (Wilson, 2012). There seems to be a systematic failure in the market to provide equitable and fair access to the health care benefits of the market that are stated to bring, as outlined in the NHS Constitution in England, Principle 1 of the NHS constitution:

> The NHS provides a comprehensive service, available to all. It is available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. The service is designed to improve, prevent, diagnose and treat both physical and mental health problems with equal regard. It has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population (NHS, England, 2015:3).

Although there has been some movement towards more inclusive health care practices such as through equality and inclusion policies, the legacy of race and racism continues to limit Black people's access to services that can improve their health. Discrimination and bias towards racial inferiority has left Black people with lower levels of human capital and unable to navigate the health service and utilise what participants in this study described as access to resources that would improve their health. See chapter 1 for a discussion about Grossman (1972) who coins the term "Health Capital", to refer to one component of human capital.

6.6.4 Health Capital and Coloniality

Many of the participants in this study spoke about some of the challenges they faced as Black people in the health market. They pointed to, for example, time to undertake physical activity as a 'luxury' as illustrating the way in which health is seen through the normative lens of whiteness that they could not afford in terms of time. They spoke about how the kind of work they did led to several hours per day going from job to job to make ends meet and how this impacted upon their health. This is an example of the evaluative space of health that is missing from welfarism approaches to heath allocation. Black people are commonly low paid, underemployed and overworked because gender and race are separated into distinct elements that are not intersectionally linked.[45] Here, women in the group,

[45] Also see Lugones (2008) "coloniality of gender" in chapter 1 for a discussion about the relationship between the intersectionality and coloniality frameworks

spoke about how their multiple identities (gender and race) intersected and rendered them powerless to adopt healthy lifestyles. In this study, I discussed two intersectional frameworks, (Collins 2015; Crenshaw, 1989) that show how the intersecting identities of race and gender, which coalesce in the site of the Black woman leave her unprotected by legal frameworks assigned to separately protect both identities. In this chapter, I apply intersectionality in a wider context that goes beyond the intersection of race and gender but extends to the economic market failures (i.e. “coloniality of power” and “coloniality of gender”, see Quijano (2007) and Lugones (2010) respectively) that deny access to health prevention activities. This point about “coloniality of gender” is crucial to my study because a significant number of Black families are headed by women and they are also more likely to be single mothers who rely on their sole income (Rosenthal, 2016). Caribbean and African people, particularly women, are more likely to be less physically active than those from the White British or White other groups which can lead to a higher burden of disease (Shoneye, 2011).

Historically, W.E.B. Dubois (1899) wrote in the 1890s that since the abolition of Slavery, many African Americans remain enslaved to poor health and care, in terms of a “coloniality of power” in health care, as discussed in chapter 1, we can see this continuing to happen over a hundred years later in the UK. Despite improvements being made in white majority populations around some health conditions, this has not occurred for those in the Caribbean and African communities (Grey, 2013; Knight 2019). It is the limited access to appropriate information to improve the health of Black people that I refer to as “enslavement” in this context. To illustrate this point, I will briefly outline two national enquiries that have shown high rates of deaths in Black people, but the level of attention needed to address the disparity has not yet materialised. Firstly, the Confidential Enquiries into Maternal Deaths (CEMD) have been publishing reports into maternal deaths for over sixty-eight years and although they did not start collecting data on ethnicity until 1994, they suspected that there were higher rates of mortality of Black women. Since 1994, data has consistently highlighted disparities in maternal mortality rates for Black women in the UK. Knight (2019) reports one of the starkest health disparities for Black women; they are five times more likely to die as a result of their pregnancy. Secondly, the National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD) of patients with Sickle Cell Disease (SCD), which is a genetic disease largely inherited among people from the African Diaspora reports contributory factors for high rates of mortality due to a lack of

investment in equipping staff with the skills to care for patients with SCD (Lucas, 2008). This included a lack of monitoring, lack of referral to specialist staff, inadequate pain management and a failure to undertake proper assessment of the patient's symptoms that could have been unrelated to their SCD.

In summary for this synthesised theme, there is a recognition that policy implications of discrimination can have a direct impact on the health experience of Black people. This theme also raises an important question as to why do public health policy, interventions and practices continue to fail to address health disparities by not using race and racism as one of the wider social determinants of health? This takes us back to our discussion in chapter 1, about decision-making, where there are a number of ethical and moral questions about "just" and who decides what "just" is. In chapter 1, I discuss the decision-making process in the QALY (Quality Adjusted Life Years) regarding the quality and value of one's life and conclude that anyone who can decide "just" has the power.

6.7 Overarching Theme: Decision-Making, Implicit Bias and Gatekeeping

Participants alluded to decision making biases that affected their health choices and challenges in accessing a health system that considered the needs and differences of Black people. They spoke about the way in which decisions were made that did not meet their needs as Black people. Some of the discussions across both phases, expressed the limited access to resources and gatekeeping that prevented them from delivering services for their communities. This was particularly expressed by voluntary sector leads that experienced barriers to resources but were still used by mainstream providers to deliver where there were gaps in provision for Black people. This theme builds upon discrimination in policy making and how participants expressed the lack of access to resources, gatekeeping practices and decision making that influence health outcomes.

6.7.1 Decision-Making and Implicit Bias

In this study, many of the participants did not see the health care market as an instrument used to deliver health care benefits because it neglected their specific

needs. Participants talked about the lack of equal access to the market, which resulted in poorer knowledge (education capital) of choices and poorer decision-making processes in terms of achieving positive health states.

In chapter 1, I spoke about the QALY decision-making process that assigns a financial value to patients based upon the effectiveness of a treatment and the potential health benefits of clinical and treatment options. The NHS has finite resources and the QALY is used to ration those resources to discriminate against those deemed to have less 'life years' in good health and thus, more expensive to treat. I also strongly suggested that the QALY itself is structurally racist and an inequitable measure because it places a lower value on the lives of Black people because as discussed, Black people have higher rates of mortality and morbidity at earlier ages across a number of indicators in comparison to the White population. As discussed earlier, the social determinants of race that lead to ill-health are not accounted for in the evaluative space, so the QALY continues to have a stubborn blind spot concerning Black health outcomes. To illustrate this point, several participants spoke about implicit bias when discussing conditions that disproportionately affect Black people such as Sickle Cell Disease (SCD) which receives seed-corn funding that is inadequate to provide a comprehensive service of unmet needs by the mainstream. Comparisons in the US and UK between SCD and other conditions highlight that although SCD is the most inherited disorder predominantly amongst Black communities, cystic fibrosis that affects predominantly White communities, receives more funding, investment and attention (Kushnick 1988; Bahr, 2015; Farooq, 2020). Earlier arguments around "just" return to reinforce this example.

The participants expressed this argument from an individual and a community-wide perspective highlighting the lack of representation they felt that they had in decision-making positions. For them, this meant that their voices were unheard (or hidden) concerning their specific health needs.

6.7.2 Gatekeeping and Representation

In terms of gatekeeping, participants, in particular spoke about the lack of senior representation of Black people in decision-making positions when they had clinical or professional encounters with health service personnel. Historically and from a colonial perspective, the NHS continues to benefit from the influx of Black people

being recruited to work in the NHS from the UK and from former colonies, which continues to build and sustain the health care service. Research from the Coronavirus pandemic highlights a disproportionate number of Black people and other ethnic minority health professionals at all grades that have died from the disease (ONS, 2020). Yet, regardless of the price Black people have paid for their service to the NHS, since arrival during the Windrush era, there is still a perpetuation of the health disparities that can deny Black people access to free health care with for example, the surcharge or those with No Recourse to Public Funds (Williams, 2020).[46] NRPF deny women access to essential maternal care unless they can pay the £7,000 or more NHS charges. Black women are less likely to be able to afford this charge which further compounds the health disparities that can lead to maternal mortality and morbidity.

The NHS is the largest employer in England and plays a significant economic role in the health of local communities; despite this, the NHS health care market is not the perfect market, as I discussed in chapter 1, where racial classification appears to privilege White communities to power and access to resources (Williams, 1995). Although the Equality Act (2010) places a lawful obligation on public bodies including the NHS to eliminate unlawful discrimination, these systemic racial categories perpetuate a colonial hierarchy that maintain the power structures that disadvantage Black people.

However, the racial hierarchy of Whiteness (i.e. “coloniality of power”) continues to pervade the NHS causing barriers to the upward mobility of Black people in the workforce, where there are also higher levels of unfair treatment including bullying and harassment from service users and staff (Broad, 2018). Black professionals are also more likely to be involved in fitness-to-practice cases than majority groups (Rimmer, 2015) and at the same time, they are more likely to be assessed more rigorously and unfairly in their training (Klein, 2014). We also need to acknowledge that healthcare system leaders in decision-making positions are usually White and male-led, which does not ensure that there is diversity of thought to represent the communities whom they serve (Klein, 2014). Although not necessarily causal, practices of poor treatment and blockages of Black staff progression exist despite the evidence base that identifies the health gains for patients by having a representative workforce at all levels of the care delivery system (Francis, 2013;

[46] See chapter1 for a discussion about the No Recourse to Public Funds (NRPF) that is a system that denies access to Public Funds people with no leave to remain, illustrating an example of “coloniality of power” over race and access.

Kline, 2014). Here, I am describing habitus (field) in practice. See chapter 1 where I discuss habitus as "the way society becomes deposited in persons in the form of lasting dispositions, or trained capacities and structured propensities to think, feel and act in determinant ways, which then guide them" (Wacquant 2005: 316, cited in Navarro 2006: 16). If we look at the NHS as a field, Allen (2011) describes it as highly institutionalised and as such, it can be resistant to change.[47] Some of the participants in this study were representative of lower ranked health professionals that experienced racial barriers to progression and I included references to this in my own experiences in chapter 1. For many Black people of my parents' generation (Windrush), there is a strong sense of pride about working in the NHS yet there are frustrations about the continued barriers of a health system that works to disadvantage and marginalise Black users and well as its workforce. This has been recognised in the NHS Workforce Race Equality Standard (WRES) which seeks to develop ways to ensure that Black and minority workforce are treated fairly in the workplace and have fair and equal access to career development.

6.7.3 Gatekeeping and Racial Bias

There are historical stereotypes of race that influence the clinical encounters between Black communities and their medical or health professionals. Research has shown that there is a tendency to use stereotypes when engaging with Black people and this extends to clinical encounters (Burr, 2002; Green, 2007; Watson, 2019) and participants spoke about the assumptions that were made about them in my findings. There is evidence in the UK and the US that health professionals will harbour unconscious and often conscious racial biases which might have developed through socialisation during childhood, networks and in society at large (Van Ryn, 2011; Kline, 2014; Kapur, 2015). These can lead to stereotypes guiding certain practices in medical and nursing education curricula. Racial bias can negatively influence the way in which health care professional diagnose and treat Black people. Some women from my study said they were not given listened to during their encounters with predominantly White health professionals and that assumptions were made about their need for certain medications (Campbell, 2012; Abdou, 2014; Haye, 2020). Their biases cause them to give Black people

[47] Also see chapter 3, where I make similar observations about habitus, academia and my insider/outsider status.

inferior health care and, in so doing, contribute to higher rates of morbidity and mortality, which today are seen in structural racism that has resulted in disproportionate maternal and infant death among Black people. To broaden this issue, Foucault (2007) asserts that biopower (which is a term he coined and one which I spoke about in chapter 1) exercises how institutions control the human body as a 'social good' at both a macro and micro level. From a Foucauldian perspective, power can serve to disadvantage Black people in the health market because they do not fit into 'normalised' majority White population categories that aim to address certain health care needs. Decision making is Eurocentric and principally made by those who hold Power (normally White men in the habitus as described by Bourdieu, 1977) in relation to how resources are allocated and determined. An example highlighted by participants in phase 1 spoke about the images used in health prevention that do not reflect them and their cultural needs such as foods. Participants in "Consequences of being Black" cited how practices undertaken by medical and nursing staff that referred to skin and hair and how their diagnosis of skin conditions were often delayed as practitioners were unaware of how differences were presented in Black people.

6.7.4 Racial Bias and Standardisation

Racial bias can feed into a negative feedback cycle where Black women, in particular (due to "coloniality of gender") can be discouraged to engage with healthcare practitioners because of the perceived or actual experience of discrimination or poor care. Participants in my study shared examples of when they avoided health care encounters because they either experienced poor treatment or perceived they would receive poor care because of the experience of others. There are narratives about screening for black people that are operated within a system of biased decision-making in that people need to meet a criterion that was standardised against the majority population, these include for example a health check at 40yrs old. This standardisation is biased but also leans to majority populations in ways that can be to the detriment of the health of Black people. For example, research undertaken in the 1980's by Culyer (2012) who highlighted that pulse oximeters are unlikely to detect accurately oxygen levels in the blood of dark-skinned individuals due to the levels of melanin. This tool used to measure oxygen levels can underestimate hypoxia leading to inadequate There is a market assumption that all groups are likely to contract diseases at the same

age as other majority groups (Culyer, 2012). The participants shared many stories of people they knew about, that (to their detriment) struggled to get tested for prostate cancer before 50 years old because this was normalised as a common occurrence in this age of the UK majority population.

6.7.5 Policy Implications for Black-led Organisations

One of the themes that came out strongly in the study highlighted covert discriminatory practices, which participants identified as blocking access to improved health. In phase 2, focus group, four out of the six participants led community organisations that focused on care delivery to Black communities. There were several frustrations felt about the lack of investment to meet the needs of Black communities despite poor satisfaction from mainstream services. Participants expressed that the health care system was unfair and that Black communities were not allocated the level of resources needed despite having the greatest need across several health indicators. Participants believed that this was based upon existing stereotypes about Black people not being intellectually able to manage funds. As a consequence, White-led organisations they knew about were given large sums of core funding to manage whilst leaving available what some participants described as seed-corn project funding that could not sustain their organisations to efficiently deliver their essential initiatives (Chouhan, 2004).

The Macpherson report (1999) defined institutional racism as the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin (Macpheson,1999: para 6.34). The processes, attitudes and behaviours inherent in the health service can be described as institutionally racist (Brady, 2010; Braithwaite, 2018). They keep Black people marginalised because they do not share ownership and leadership in decisions which shape the lives of Black people and sustain health disparities (Kalra, 2009; Priest, 2015; Salway, 2016; Francis, 2013; Klein, 2015; Banerjee, 2018; Lammy, 2017; Fenton, 2020).

In speaking to external perceptions of institutional racism, the participants spoke about the lack of balance in decision-making when they were invited as community leaders to be involved in decisions made about services after agreements had been made and signed. They talked about the drain and stress on themselves and the isolation difficulties they had when they proposed changes as the only Black person in the room, which were often not taken forward. White privilege can

diminish our lives and breed anger within our own communities, aspects of which the participants shared when describing their poor treatment.

From a community perspective, this view acknowledged the health capital that Black people have in their communities to enable them to do things for themselves and increase their own health experience. However, epistemological knowledge created by Black people is deemed not to hold the same value because Black people have been denied entry to the field that could increase their social capital (Bourdieu & Passeron, 1977), as discussed in chapter 1 with the Grossman model (1972).

6.7.6 Self-Empowerment and Gatekeeping

Despite the lack of value placed in Black epistemological knowledge, gaps in mainstream provision have stubbornly persisted and have led many communities to set up their own organisations to address the needs of Black people. Historically, Black-led organisations were largely set up in the 1950's when many people from the Caribbean and later on from the African diaspora were invited to fill jobs after the World War (Olwig, 2017). These organisations have notoriously been underfunded by the government agencies, as previously discussed, leaving Black people to continue to be challenged with unmet health needs. Participants in the study spoke about how these groups provided culturally appropriate information to help navigate Black people through an unequal system in the UK. Participants expressed that even though their services were often cited as valuable to the community, it was not reflected in the overall decisions that agencies made to fund their work or to address their health needs, even when Black-led organisations provide evidence of impact and the research is also provided to conclude that they are best placed to meet the needs of Black people (Memon, 2016). As the participants stated, they lack the level of investment by agencies and often loose out to larger national VSCE sector organisations that are not representative of their community. The participants strongly suggest that there appears to be a bias in decision-making. In chapter 1, I discuss in more detail the habitus and gatekeeping that create these barriers of access to people that are not in the field (Bourdieu,1984).

In summary of this theme we can see that decision-making that positively impacts health is generally only afforded to White people (especially from wealthier socioeconomic backgrounds) who tend to be in networks where they share power and privilege that as discussed, are often denied to Black people. In the Policy Implications of Discrimination theme, discussed earlier in this chapter, we saw that failing to include race as a social determinant of health had a deleterious effect on policy making for Black health. However, in this theme, we see that even when representatives of Black organisations are around the decision-making table, their experience and expertise around the health needs of Black communities are ignored.

At a community level, where Black organisations are trying to help themselves by looking after their own health (as everyone is encouraged to do by wider health promotion campaigns), this form of structural racism actively denies them access to the field, in so doing, denying them influence and an experience of fair, non-discriminatory practices.

The hidden question this theme brings to the fore is; if the health market encourages individual and collective responsibility for healthy lifestyles, why does it, via a clear lack of investment, disincentivise Black-led community health organisations, who want to do just that, for their communities? There would appear to be a strong “coloniality of power” that is dictating to Black communities who they must accept help from, which deliberately removes their collective agency.

6.8 Power and Impacts upon the Community

Throughout this thesis I have highlighted the importance of how power and how various forms of Power has played its part in restricting the rights of Black people from having better health outcomes. This final synthesis theme illustrates how this thesis interrogates the decoloniality of Power within the health of Black people and how it negatively leads to those health disparities identified earlier in the literature. The themes from the finding’s chapters illustrate how Power manifests itself through the experiences of the participants.

The experiences of the participants in this study highlight the overall consequences of being Black in a society that racially disadvantages them. The antidote for being Black and the privileges denied can be felt through the power structures that participants spoke about in relation to access to health and lack of

inappropriate interventions to address health needs. The racial tax (Akom, 2008) that I spoke about earlier on disadvantages Black people for being Black and increases their risks of poor health because it limits access to the health market. However, and often unintentionally, White people benefit from being White and receive a racial wage (i.e. a psychological wage, see DuBois, 2008), even if White people are in fact socio-economically or educationally worse off than some Black people. Without Blackness, Whiteness could not exist to maintain the power dynamic between those that are marginalised and those that have privilege (Fanon, 1989). This is how Whiteness and Power work synchronously to the advantage of Whiteness which denotes Power and privilege.

Throughout my study, I examine the role of power and its part in both limiting any changes from taking place, as well as facilitating them. The table below uses the themes from my findings in Chapter 5 to illustrate how power affected my community participants. The table illustrates the theoretical elements of Power, where its application results in poor health outcomes for Black people. The table is also an example of praxis, where I show how both the theory and practice of Power come together to impact (negatively) on Black peoples' health.

Overarching Themes from Chapter 5	Sub themes from Chapter 5	Theoretical forms of Power	Negative effects of Power on Black people (Praxis)
Significant Influences on Individuals	"Our own internal matters"	Power acting to make resources scare Coloniality of Power (Mignolo, 2007) Bourdieu's habitus (1984)	The systematic barriers to resources to meet the needs of Black communities create internal rivalry and the 'crabs in the barrel' mentality for seed corn and or resources. This creates disharmony and stresses in the community that impacts their health.
Discrimination	"It is never about meeting our specific needs"	Power choosing to exclude along cultural lines Habitus (and taste making powers) (Bourdieu, 1984) Matrix of domination (Hills Collins, 1990) organising intersecting characteristics at societal level to bolster taste-making powers of habitus.	This prevented Black people from engaging with health services. Black people saw themselves as 'second class citizens' and would be deterred from seeking treatment early enough. This often led to delayed interventions that were more difficult to treat
Mirror of Black Health	"it happened to me, my mum and her mum"	Intersectional impacts of Power and how it is passed down generationally. Coloniality of Gender (Lugones, 2008) and Matrix of domination (Hill Collins, 1990) Intersectionality (Crenshaw, 1989) Post Traumatic Slave Syndrome (PTSS) (DeGruy, 2005)	Stereotypes of Black women as aggressive, low threshold to pain, created intergenerational stresses that results in the perpetuation of epigenetics health challenges

Table 7 – Illustrations of Power & Practice

In "Significant influences on Individuals" the table highlights how power is not equally shared between White and Black people in the health care system, in terms of access to health and how this produces scarcity. Although scarcity is a natural feature of the limited resources in health provision for everyone (see Chapter 1), a lack of equal distribution of these scare resources disproportionately disadvantages Black communities causing them to fight over fewer resources they do receive, whilst observing comparatively greater investment in health of the white majority population. The criteria for resource allocation that causes inequality is a key feature of the impact of Power on Black communities that was discussed in Chapter 1. Black people have worse health outcomes overall even after controlling for socio economic status, therefore, knowledge and understanding of how Power influences decision making for

marginalised communities can aid in allocating appropriate resources and access to health service benefits.

The overarching theme, “Discrimination” illustrates the way in which health systems are set up along colonial lines (i.e. “coloniality of power”) where the biases within the system and the resulting power (habitus) of the gatekeepers continues to maintain the White body as the standard template for determining health needs and priorities. Participants described how they felt that health promotion consistently did not meet their needs, as they pointed to cultural issues which they thought the health professionals were either unaware or ignored. This feeling of being ignored manifested in the sentiment of feeling like a “second class citizen”. The use of the word “citizen” in this context implies a societal level of organisational oppression (matrix of domination), along, as they saw it, cultural lines that can also be described in intersectional terms.

In “Mirror of Black Health”, I illustrate how Power manifests itself through the intersections of race, gender and colonialism (i.e. “coloniality of gender”, matrix of domination, intersectionality and “coloniality of power”) and how it is an ongoing reality in the lives of Black people and one that produces health disparities. This was evident through the narratives of the participants which emphatically highlighted how Power limited change for them even at an intergenerational level (i.e. PTSS) whilst seeming to facilitate and maintain privilege for White majority populations.

In summary, Power is the thread that is embedded throughout this thesis where policy and practice decision-making by gatekeepers control the health market. The hidden factors articulated by the participants revealed that the postcolonial structure of the health care system determined how they were treated within the health market. The different forms of Power including Bourdieu’s (1984) “habitus” , enabled me to tease out the presence of Power from the colonial discourse that determined the set-up of institutional structures and the controlling factors within the market, which I identified as habitus, gate-keeping and implicit bias.

6.9 Summary

In this chapter I have outlined that for Black people, behaviours and lifestyle choices are shaped by historical factors that have formed the disparities we can evidence today. I conclude that it will require time, cultural sensitivity and humility to change mindsets about the impacts found in the study on the health of Black people. The conditions in which Black people live is surrounded by a legacy system that produced racial hierarchies resulting in a deprioritisation of Black people's health needs. These outcomes evidence how public health which is to prevent disease, promote health, and prolong life among the population as a whole' (Acheson, 1988) and health economic tools such as the QALYs does not use a racial lens to ensure that this fairness and equity is achieved for all. These racial hierarchies and those with racial biases can guide decision-making at all levels and assign privileges towards White people. Through CRT and intersectional theory, the findings in this study were able to hear the voices of the participants and unpack the roots of discriminatory stereotypes that keep Black people in poor health or disconnected to each other as communities. It highlights how power is the driving force behind health disparities and how power is created and sustained by Whiteness that is embedded in its structures. All forms of racism and gender discrimination undermine progress and it is important to address the intersectionality' of race and gender, race and faith and faith and class when seeking to identify the hidden factors maintaining health disparities. This is an important aspect in the decolonialisation of health care which will enable fair and equitable provision of health care to Black people. In the next chapter, I will make recommendations for ways forward that will foreground the decolonial aspects of my study. It is important to note that in discussing the epistemologies and colonial ontologies of the Black communities in this study by looking at their cultural and social capitals (from alternative remedies to cooperative economics to aspects of community theology and its potential for decolonisation), I have been approaching this entire study with a decolonial lens that has sought to uncover the hidden structures of the "coloniality of power" in health care.

In the final chapter, I will describe how Power could be made to facilitate positive change in health outcomes for Black communities, as I outline the health advocacy that is happening on the ground and the recommendations that I make as a result of the advocacy work.

Chapter 7

CONCLUSION and RECOMMENDATIONS

7.1 Introduction to the Chapter

I would like to start this chapter by reminding the reader of the overarching aim of this thesis, which was to explore the hidden factors influencing the persistent health disparities in Caribbean and African Communities in Greater Manchester (GM). The motivation for this thesis stemmed from the personal experiences I had encountered in my life as a Black woman, mother, academic and health professional. Therefore, it was my intention to take the reader through a journey of ethnographic exploration and evaluation of the Black health-seeking experience that branched out from my own reflective experiences of myself, my family and friends to the wider community. With that, I took a deeper look at the influences on health and health care provision through the eyes of the wider community, as represented in phases 1 and 2. I then continued this exploration and evaluation by touching on community-perceptions of the health system in Greater Manchester and by examining existing health and health care literature, both of which allowed me to end this chapter with recommendations for advocacy based on my findings. My recommendations will also come from some of the ongoing advocacy work with Greater Manchester Combined Authorities (GMCA) stakeholders that started as a result of this critical ethnographic study.

I had three research questions below and using the lens of CRT, Intersectionality and post/decolonial theory, I found a number of influences behind the health disparities and poor health outcomes experienced by my participants. In this final chapter, I summarise my study and include my contribution to knowledge along with my recommendations.

7.2 Summary based on my Research Questions

This thesis set out to answer three questions and here, I summarise how these questions were answered in this study

Research question 1: How is public health information understood, made sense of and experienced in the lives of Caribbean and African people in this study?

In my findings, participants expressed that public health information was not very relevant to them because it was not representative of the cultural backgrounds that they were familiar with and understood. It was evident that although the public health messages were meant to be preventative, the information, whether verbal or written, was not clearly understood in relation to how they could apply these health prevention messages to their daily lives and prevent the health disparities across several conditions.

Research question 2: What do the voices of Caribbean and African people tell us about their health experience and its influence on health outcomes?

The voices of the participants told us that they are not very well represented in GM health care decision-making and they felt that their attempts at taking collective responsibility for their health were undermined, underfunded and unsupported. The participants highlighted the discriminatory practices that result in limited access to the health market and a lack of overall investment in their health. They spoke about how both internal (intra-community competition) and external (stakeholder discrimination) practices impact on their health, creating stressors that result in poor health.

Research question 3: What are the perceived (from a communities' perspective) professional health care behaviours and attitudes that produce poorer experiences for Black People?

From the communities' perspectives, participants pointed out the discriminatory ways in which they are treated within the health system and society at large and how this produces health disparities. They voiced how relationships between communities and the system are weathered and strained and there is resulting lack of overall trust and engagement with services. They said that they wanted more social and financial capitals and networks to influence change. They want greater representation of Black people in senior positions of health care commissioning bodies and provider services to influence a change that considered and acted upon their health needs. Participants wanted equal unbiased decision making to be made with them so that their health (from a cultural, racial and religious perspective) could be given equal consideration and attention as given to majority White populations. They also pointed out the need for greater

transparency in terms of how commissioning decisions were made and what their equality impact assessments were.

7.3 Reflections of the Research Findings

This section offers a reflection of the process through this thesis which demonstrates how my research journey uncovered a group of Caribbean and African health seekers access to health. I began this study by acknowledging the clear racial disparities in health for people of Caribbean and African origin in the United Kingdom.

Through the literature review in the UK, studies highlight the higher prevalence of poor health conditions and a disparity of worse outcomes leading to increased mortality. However, these studies have attributed the propensity of health disparities and poorer health outcomes to socio-economic status, cultural factors and biological characteristics. In my study, I identified the associations between health and other concerns (i.e. social, cultural and socio-economic) from the participants so that there was a clear picture of what the hidden factors were impacting on the persistent health disparities in these communities. The study makes clear that Black people have inherited a postcolonial legacy of racism. Through the voices of Black people in this study, I have attempted to make sense of how these legacies impact on contemporary health disparities.

The thesis provides an evidence base that recognises that structural bias (racial discrimination) in the health market results in health disparities for Caribbean and African health seekers. Participants revealed several threads that were weaved throughout the study as they spoke about their health issues, health seeking behaviours and barriers to the health market using intergenerational terms of reference. From the voices of the participants across both phases of the study, I can conclude that there are discriminations and bias in decision-making that create barriers to health.

The research study adopted a critical ethnography methodology to “hear” (acknowledge) and interpret the often-silent voices of the participants as they shared their everyday lived experiences. In chapter 6, I unpacked the voices of the participants using the sociological frameworks of Critical Race Theory (CRT) and Kimberlé Crenshaw and Patricia Hill Collins' iterations of intersectionality.

These frameworks were used to theoretically underpin the contemporary narratives of the participants. I then took aspects of post/decolonial theory to unpack their voices and uncover the historical gaps in access that the participants implied during the focus group sessions.

The participants' voices were "heard" using a qualitative design comprising of focus groups, and fieldwork notes during two phases of data collection. This was thematically analysed by adopting knowledge co-analysis and acknowledging researcher positionality and influence. In terms of interpreting the solutions that their narratives hinted at, decolonial (coloniality) theory was used to help bring to the fore the power dynamics present in their narrative accounts but crucially it was also used to help envision a future where the asymmetry of power they described was transformed into a health system of equity and equality.

Participants expressed and articulated the persistent struggle to obtain value, visibility, respect in terms of equal and fair treatment that did not treat their skin colour as a deficit. The participant-narratives showed how the legacy of colonialism could result in intergenerational trauma and epigenetic changes that arose from both internal disharmony (community) and external factors such as racism and discrimination, stereotyping and benchmarking in favour of White majority populations. Many of the participants especially in phase 2 accepted stress as a facet of their lives but showed how they were often able to create health capital in their own environments, such as the Church.

The hidden factors articulated by the participants revealed that the postcolonial structure of the health care system determined how they were treated within the health market, more widely. This resulted in teasing out the presence of power from the colonial discourse that determined the set-up of institutional structures and the controlling factors within the market, which I identified as habitus, gate-keeping and implicit bias. Of key importance through these often-silent voices was the theoretical interpretation of the lived experience and how this pointed to how power was distributed and manifested in racially discriminatory policies and practices and the persistence of health disparities that continue to worsen over time.

The findings in the study revealed a range of contemporary barriers and gaps in access to the health market that have postcolonial echoes, which will require a combination of post and decolonial scholarship, health advocacy and political activism to mount a sustained community campaign for structural change within

the health sector. Decolonialisation seeks to eradicate, hegemony, power and control relating to the unequal burden on the so called 'inferior races' that is a legacy of white European (Eurocentric) values. The study showed how public health requires a "decoloniality" of the sector and how it needs to address the systemic biases that prevent Black people from improving their health outcomes. The study also demonstrated the need to dismantle racism that health systems depend upon. With the help of my participants' narratives, I demonstrated an urgent need to look at where these power structures come from (i.e. identifying and addressing the "coloniality of power" in health) so that the we do not continue to perpetuate the same views and stereotypes that bring disadvantage to Black people. From a critical ethnographic positioning, I examined the findings in the context of current policies and practices, with a view towards influencing a decoloniality of health care policies and practices to improve health.

7.4 Limitations of the Study

The aim of this study was to gain an in-depth view of the how Black people access health and to explore those through the stories of how that access impacted their daily lives. There were some limitations to this ethnographic study that would have helped to provide a deeper insight into people's lived experiences. For instance, even though I was able to uncover the hidden "coloniality of power" at play in their experiences of health care, I did not explore the decolonised aspects of community knowledge that they shared, which included discussions around traditional remedies and cooperative economics. As alluded to in chapter 6, Black men do not easily fit into Crenshaw's original intersectionality framework of race and gender. This was a limitation of this study as this framework, in my opinion, does not go far enough to include Black men in intersectional enquires about the impacts that race and gender have on their health. However, this points to a wider critique of intersectionality that questions its methodological framework (Nash, 2008; Werbner, 2013). My study pointed to a 'real world' need for an intersectional framework that acknowledges the interplay between marginalisation and privilege that exists within all subjects. Nash (2008) reminds us that marginalisation is not a homogenous entity. If we take the case of the 'Black Woman', her race and gender is inflected by her class, sexual orientation and even her historical

context.[48] Nash goes on to say that these inflections in some cases can act as vectors of privilege to offset elements of marginalisation to create a subtle and nuanced intersectional experience for her that extends beyond her race and gender.

This unresolved methodological dilemma is expressed by Crenshaw (1991:1244) herself when she writes, "the concept of intersectionality [is used] to denote the various ways in which race and gender interact to shape the multiple dimensions of Black women's employment experiences" but she later concedes that "my focus on the intersections of race and gender only highlights the need to account for multiple grounds of identity when considering how the social world is constructed." In my study, where I specifically examined the social identities of Black Men and their impact on health seeking behaviours, it was important for me to use an intersectional framework to explore their "multiple grounds of identity" which took into consideration their male privilege as well as their racial marginalisation, which is why I used the term "multiple identities" (Werbner, 2013).[49]

This discussion about the internal methodological issues within the analytical framework of intersectionality constitutes the evaluative space in health that current welfare models of resource allocation do not really address, which could explain why change for Black health seekers has been so slow in coming. I think greater exploration of these issues would have given a stronger lead into re-discovering what pre-colonial holistic knowledges of health, healing and health care (i.e. community cooperation) could look like within a contemporary UK African and Caribbean Diaspora context.

7.5 Strengths of the Study

The central strength of the study is how it traces the historical origins of racially discriminatory attitudes towards Black people and how they still fundamentally exert influence ("coloniality") on health decision-making in the UK, today. The narratives that I collected really helped me to sharpen my theoretical grasp of

[48] I would also add skin tone, here, as colourism and privilege are important historical social influencers, in the Caribbean, in particular that still have contemporary echoes in these diasporic communities (Austin-Broos, 1994)

[49] Although I recognise that Werbner's use of this term denoted what Nash would call privileges instead of the analytical mix between the two that I had intended.

those decolonial themes running through my study. This grew through having the conversations with the community. The more the spoke the more it led me to research and understand some of the theoretical and historical points they were making in the literature.

The study's strength also comes from it being a piece of decolonial scholarship that interrogated the hidden power structures within the health market. Using an interdisciplinary framework consisting of intersectionality, critical race theory and decoloniality, the study explored the intersection between the "coloniality of gender" and the "coloniality of power" and its devastating effect within the health market for Black women and men. It is innovative because, as mentioned earlier, it is an interdisciplinary piece of research that combines public health, critical race theory, post/decoloniality, intersectionality and health economics to look at health disparities for Black people in the UK.

Another innovation of this study was how the often-silent voices of the participants could resonate and be "heard"; where embedded decolonial theory (i.e. community knowledge without the academic vocabulary) was excavated from their narratives to help bring to the fore the power dynamics present in their accounts. However, crucially, their embedded decolonial knowledge also helped us to envision a future where the asymmetry of power they described was transformed into a health system of equity and equality.

Although some improvements to ensure equitable healthcare have undoubtedly been made, to date in the UK, these historical and often hidden influences have not been explored. This is important because these postcolonial echoes are embedded within how the health market operates, producing ongoing barriers to health.

I was able co analyse some of the data in terms of prioritising some of the themes that they wanted to discuss in phase 2. This is co-production because my participants in phase 1 helped me to decide what the themes should be

Another strength of this study came from the opportunity to harmonise my personal experience (autoethnography) with the experiences of others using critical ethnography and also in many ways my positionality, which enabled me to collect the data I needed to examine the communities lived experiences.

7.6 Contribution to Knowledge

The thesis makes an original contribution to knowledge in several ways and I hope that this new knowledge will continue the work that I have started to inform the application to policy and practice.

My contribution adds and recognises that there is a paucity of UK published qualitative studies that focus on the centralising of voices from Caribbean and African communities to gain an understanding of their lived experience and what they identify as the factors sustaining health disparities. Through the voices of Black people in this study, I have made sense of how these legacies impact on contemporary health disparities.

The study adds an in-depth historical underpinning of race and the ways in which racism influences sustained health disparities experienced in Black communities. It recognises how health systems (such as public health) and frameworks do not use a racial lens to ensure equitable health outcomes for the Black community. This work therefore contributes to knowledge because it offers a combination of critical theory and decolonial theory to examine influences on Black health.

The study specifically adds to the literature a theoretical underpinning of the often-silent voices of Caribbean and African health people, which through their everyday lived experiences of the health system, describe the historical (postcolonial) foundations for today's health disparities.

The study provides theory generated from the findings that can help to plan and design policies and practices that recognise and mitigate the factors identified that sustain the poor health of Black people.

The voices of the participants give health providers insight into the ways in which their engagement with health care can be better planned and resourced to avoid the inequitable burden of disease.

Understanding the intergenerational physical and mental impacts of trauma can help to initiate early childhood intervention to avoid later health, mental and wellbeing challenges that perpetuate health disparities.

7.7 The Impacts arising from this Study

Two key pieces of work have arisen from the data within this study and provide concrete examples of the ways in which critical ethnography can bring about action and change in research. Following the data collection and the continued use of my field work diary, I was able to use the findings to develop an organisation called The Caribbean and African Network in Greater Manchester (CAHN). This was a direct result of questions from participants when they asked what would be done with the data upon completion. I was fully aware that the community saw themselves as being 'over-researched' and they were yet to see the benefits of their involvement across numerous research studies. Because I really wanted to do something that responded to the voices of the different communities that I heard through the data collection, I decided to begin to put my findings into action, once they were thematically analysed.

Participants' feedback highlighted the overwhelming need to provide tailored support and education around several health conditions. Participants stated that they could not equitably access tailored support from mainstream services. Participants then spoke about the need to have Black people in decision-making positions where they could be a voice on behalf of the different Black communities influencing decision-making in policy, practice and research. They voiced the need to bring the different Black communities together so that there could be more joined up and mutually beneficially working relationships with various communities across Greater Manchester.

A further piece of work that arose from this study and relates to the need raised by Black-led faith leaders about their inabilities to navigate the health system in order support the health needs of their congregants was funded by the Mary Seacole Awards and has had a far-reaching impact since completion of the study which highlighted the need for me to fill a gap of unmet need to address health disparities.

This next section provides a short overview stating how this organisation speaks directly to its findings and its impact since it was developed 3 years ago (see appendix 13,14,15).

7. 7.1 Caribbean and African Health Network, (CAHN) Greater Manchester (GM)

CAHN arose out of this study and is now a Registered Non-Profit Organisation whose purpose is to empower, enable and equip faith and community organisations with the infrastructure to deliver and shape health and wellbeing services. The emergence of CAHN represents how Black people currently negotiate the market but also how they can more effectively negotiate the market in the future.

CAHN GM is an infrastructure organisation that aims to work collaboratively with commissioners, statutory and voluntary sector organisations with an emphasis on sustaining health and well-being provision within the Caribbean and African community. The organisation was launched in 2017 (see appendix 13) with the ultimate focus is to facilitate capacity-building in the Caribbean and African voluntary and community sectors. The organisations works to ensure that Black-led organisations are able to deliver health and wellbeing services that are fit for the purpose of the Black communities (CAHN, 2020).

A rich research base including contributions from CAHN members, underpins the work of CAHN. From the evidence it is known and understood that structural systems, policies, practices and processes do not provide equity for black people in health prevention and improvement; CAHN wants to work with systems to deconstruct these. For example, the government's Racial Disparity Audit report published on 10th October 2017 highlights the disparities faced by Black and Minority Ethnic (BME) groups in England. When black people do get care in the health care market, they are more likely to get it late (diagnosis of HIV, cancer, mental health, etc). CAHN GM aims to work with relevant agencies across Greater Manchester to influence the direction of travel and tailor resources needed for re-dress in our community, so that care is provided equitably (CAHN, 2020).

The network aims to bring together Caribbean and African-led organisations in Greater Manchester, to work together so that they can effectively engage statutory providers to respond to the challenging health disparities. In my thesis, participants told me that this work requires joined up working with Black-led communities and proper coordination to enable it to be efficient and effective. Through continued community consultation and engagement CAHN has to date attracted over 150 community organisations and 1800 individuals that want to be

part of this movement that provides appropriate custom-made services for our Caribbean and African Communities (CAHN, 2020).

The initiative aims to work in partnership with Caribbean and African people to develop the education, awareness and skills in order to have a better chance to improve the health and wellbeing of our communities. CAHN also aims to build stronger relationships within our communities and with other stakeholders to facilitate awareness, to develop culturally specific resources, to facilitate social inclusion, equity and as a result, to improve the life chances of disadvantaged communities (CAHN, 2020).

CAHN's website: www.cahn.org.uk – this site shows how we they are responding to the voices across the Black communities.

7. 7.2 Mary Seacole – Project: Developing Health Literacy among Caribbean and African Faith Leaders and Champions to Influence Health Decision-Making at Strategic Levels.

This Mary Seacole-funded project arose from my engagement with faith leaders from Black-led churches who had some involvement with the data collection during the thesis. During consultations, Black-led faith leaders highlighted the responsibility placed upon them by their congregants for health care support as well as providing core spiritual support. I decided following discussions with faith leaders (who expressed the need to respond better to their congregants) to evaluate whether a one-day community leaders programme and two day evaluative consultation would provide the platform to develop the health knowledge of faith leaders. Twenty-seven faith leaders attended the one-day workshop which was followed up with two focus groups. In addition, semi-structured interviews were used to gather data from five strategic sector leads who presented on the day. The data was thematically analysed to generate four themes from faith leaders and two themes from strategic sector leads who attended the workshop to impart knowledge from across the health system (CAHN, 2020).

Faith leaders shared that limited health literacy, poor representation and involvement of Caribbean and African people at senior decision-making levels resulted in unheard voices from this community making it very difficult to influence and provide appropriate health services. Faith leaders also expressed on behalf of their congregants that there was a variation in access to services namely,

inappropriate and untimely treatments, and culturally and religiously insensitive practices when health services are provided across the UK. The findings from this workshop provided evidence to highlight how regular involvement between faith-based voluntary activity and health care professionals could link to greater health and wellbeing for faith members (CAHN, 2020).

Overall, this project found a wide variation of knowledge from faith and strategic leads leaders that compromised the ability to articulate the needs of their congregants and this impacted change needed at strategic and operational levels (CAHN, 2020). The project identified the need to create health literate churches as a safe space to develop healthy environments for Black people to address health dispaities, many of which were found in this thesis. Based on the findings, this project provided a real opportunity to address the health and wellbeing gaps identified in the Five Year Forward View (FYFV) (2014). This project has resulted in faith leaders working with CAHN to improve the health and wellbeing of their congregants. This collaboration has enabled more involvement in the strategic discussions with policy and practice leads across the Integrated health and social care system in Greater Manchester. The findings of the programme were due to be launched in parliament (see appendix 16) but have been delayed due to the Elections and COVID-19 pandemic.

7.8 Recommendations and where I would like Future Studies

This section of the chapter offers recommendations based on the work I have undertaken throughout the period of this thesis. I make recommendations for research practice and further exploration in this area of research. The recommendations from this study will be presented in ways that will give direction for future work that could be taken forward in research policy and practice.

This qualitative study provides a deep understanding of the lived experiences of Caribbean and African people living in an urban area of Greater Manchester. These ethnographic snapshots of the lived experiences allowed me to explore how participants accessed health and how this access influenced their health outcomes. Drawing on the data from the findings and the theoretical underpinning I make the following recommendations:

- In phases 1 and 2 of this research and the historical and sociological theory examined through the lens of CRT, intersectionality and multiple identities highlight the hidden factors that block access to the health market and sustain health disparities. Although the feedback from the System leaders that took part of phase 1 study was not transcribed and analysed, their feedback highlighted that there was a lack of understanding about the needs of Black communities in Public health prevention. Future work needs to be carried out to identify with Black communities how in practical ways, decoloniality of health care could take place to bring about the system change needed for Black people.

- Participants were clear that the health system did not recognise the cultural and religious nuances and practices that disengaged them from health prevention activities. They spoke about the benchmarking of health education and prevention information to meet the needs of White people that de-prioritised Black people. Future work needs to be carried out to explore how the health care system could be made more culturally and religiously relevant, especially in terms the cultural competency of the practitioners and ethnic representation at senior levels of decision-making. Future work needs to be carried out to explore how benchmarking to majority populations can be phased out to properly address health disparities faced by Black people. To do this, I also recommend that there needs to be a decolonial examination of existing policies and practices that stereotype and disadvantage Black people.

- There were significant discussions about the lived experiences of the participants that spoke about how the market was closed to them as Black people from organisational and individual perspectives. This was reflected in the gatekeeping and limited access to the field where decisions are being made about health care. As statutory health and care structures continue to change such as in a devolved landscape in Greater Manchester, there is a need to ensure that grassroots communities have the tools to navigate the health and care system and be involved in decision-making that will impact upon their health and wellbeing at a local level. The weighting of the Non-Goods Characteristics of race should be taken into account by gatekeepers such as NICE, policy makers in the QALY calculation to determine the allocation of resources.

- Taking into account race and racism as the basis for health disparities, future work needs to be carried out to explore how greater involvement, transparency, fairness and equity could be applied in terms of how health decisions are made and prioritised (i.e. the need for public equality impact assessments to be made available). There also needs to be a transparent process which lays bare how we remove bias and racial stereotypes out of funding contracts in relation to how they are allocated to voluntary sector organisations who are addressing gaps in the mainstream system

- Participants were clear that although there were strong internal (community) foundational relationships especially through the church and religion, there were also some community challenges that resulted in the fragmentation and breakdown of community relations and bonding. When unpacking the historical basis for fragmentation, rivalry and anti-African sentiments, colonialism explain the basis for some of this disharmony resulting in the 'crabs in the barrel syndrome'. Participants recognised that commissioners used this fragmentation and rivalry as a reason not to fund community organisations adequately. Future work is needed to explore how funding could be used to encourage inter community cooperation in the form of eliciting consortium bids for tender.

- It was evident through the lived experiences of participants leading voluntary sector organisations that despite the value-added nature of their work (as evidenced by users) funders did not allocate appropriate funding to sustain the services for them to develop. Future work needs to be carried out to explore how more funding could be allocated to Black-led organisations so that there are comparable (to other ethnic populations) levels of investment into sustainable Black-led infrastructures that could create healthy Black communities through an advocacy-based approach.

7.9 My Final Reflections

Throughout this study, I have reflected on my own everyday experiences of health as a Black woman, nurse, academic and mother accessing health and recognise how my 'Blackness' and 'femaleness' has impacted my own journey. I clearly remember the first conversations that I had when I submitted my research proposal and how I was asked about my positionality and how this could discredit the study. I refuted that and knew that positionality was something that all researchers had to be aware of and embed into their research design. I spent a lot of time reflecting on my positionality and how I would influence my research, and the connection I had with my participants. I wrote about this a lot in my fieldwork diary because even though I am from the community, I did not get the welcome I had envisaged because I entered the space as an academic, researcher and health professional. Although all of the participants had their own lived experiences, beliefs and practices to share, my own upbringing and some of the shared cultural habits and practices helped to inform this journey. In addition, many of my participants were of Jamaican heritage and brought up in the church, which helped me to connect and understand their lived experiences.

My field work diary was invaluable during the whole of this process by allowing me to highlight some very key aspects of this journey, this type of reflexivity was captured in my field work diary from my homework (pre-field) phase through to writing up my study. I used my diary to note down feelings, behaviours attitudes of participants and community gatekeepers following the various stages of data collection. I also captured some of the wider activities that I undertook as part of CAHN on the Manchester Metropolitan University's Critical Race and Ethnicity Research Cluster's website (see: https://critracemmu.wordpress.com/caribbean-and-african-health-network-in-greater-manchester-cahn-gm/)

I have reflected upon my own life whilst carrying out this study, which opened my eyes to the external and internal challenges facing Black people that result in the health disparities. I have enjoyed exploring these voices and how they have been constructed to tell this story which makes sense to me as a Black woman. I can see how knowledges are created, which stories are being told and which stories create change. It was important that I heard their stories. As I stated above, I have already begun to respond to my critical ethnographic study by implementing the findings through the community organisation, Caribbean and African Health

Network (CAHN). This is the start of a journey where through CAHN I have begun to respond to several of the above recommendations that address the basis of health disparities for Black people in Greater Manchester.

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APPENDICES

Appendix 1 - Phase 1 Session 1 Focus Group activities with Questions

Public consultation SESSION 1 – Phase 1

Overall agenda – To gain public perception of health information

Time	Activity	Who
11.00	Welcome, overview of the study and aims of phase 1 - PIS Completion and Collection of consent forms	Faye
11.10	Part 1 Introduction and summary of 3 leaflets 1) Exercise 2) Diet 3) Blood pressure	Faye
11.40	Part 2 Focus group discussions around the leaflets framed within 3 questions facilitated by students Students to collect comments and write on flipchart for each group Question 1: How is this relevant to me or those close to me (those I care for): What is my understanding of the leaflet (intention rather than how it is perceived) Question 2: How Do you think that the information provides the opportunity for you to improve your health? (or that of your family?) Question3: Are there any barriers to using or accessing this type of health information? Where do you get your health information from? Question 4: Do you think that people of African or African Caribbean descent	Faye - collate comments and do a quick analysis – into themes from flipchart

Appendix 1a - Phase 1 Session 2 Focus group with questions and activities

Public Consultation SESSION 2 – Phase 1

A view from a strategic lead in Greater Manchester Health and Social Care Partnership – Health priorities

11.00	Welcome, overview of the study and aims of phase 1 – PIS. Completion and collection of consent forms.	Faye
	Part 1 Introduction to [redacted] Talking about health care priorities in GM Devolution	[redacted]
	Part 2 Focus groups discussions – same groups as last week Student to collect comments and make notes on flip charts Question 1 Looking back on last week's sessions and themes Views around health priorities Question 2 What it is like being a health seeker in Manchester Services available to meet health needs, access Question 3 How do participants see themselves in decision-making? Involvement of Black people Community and support	Faye to collate comments and views from tables - quick analysis feedback

Appendix 1b - Phase 1 Session 3 group with questions and activities

Session 3

11.30 – 12.10

Discussion (30mins) then feedback (10mins)

Questions

1. What are the challenges you face in relation to promoting healthy living/ healthy lifestyles?

2. How can Public Health bodies help with creating the right messages about healthy lifestyles for your community and getting them across right?
3. How do you think your community could best engage with Public Health organisations?

Questions

1. What messages would support mental health and wellbeing? (reduce stress, improve resilience)

2. How can access to healthy living services be improved?

3. How can access to screening and immunisation services be improved, ie. Breast/ bowel/ cervical screening, AAA etc, NHS Health Checks, flu vac, pneumo vac, shingles vac?

Were there any unexpected or unanticipated findings?

Session ended with a summary of findings from today discussions

Questions that followed the summary of session findings

1) How can the community gain access to resources that can be shared with the community members? Asked this question in relation to devolution and changes to the NHS
2) How to signpost people and refer people to services

My further analysis linked to elements of the conceptual framework

Appendix 1c - Phase 1 Session 4 Focus group activities with questions

Part 1 - 6 themes most representative generated from previous weeks of discussions

1) **Conduct a poll and individually rank each theme from the list**
2) Provide your own reasons for your ranking
3) **You need to end up with 1,2,3 etc next to chosen theme**

Themes

Number	Themes	Ranked
1	Barriers to accessing information and resources	
2	Lack of tailored information/education about healthy lifestyle	
3	Importance of faith and culture in health decision making	
4	Limited contact from health professionals in the community	
5	Limited confidence to challenge health professionals/service provision	
6	Poor cultural and religious awareness from health professional to improve and promote health	

Appendix 2 – Phase 1 Evaluation form template

Public Consultation Evaluation Form

I would appreciate if you could take a few minutes to share your opinions on the consultation sessions

Thank you.

Please Circle which session/s you attended:

21st July: Session 1 – Exploring Information leaflets
28th July: Session 2 – Exploring Health Inequalities [redacted]
4th August: Session 3 – Public Health England – [redacted] – One You
11th August: Session 4 – Evaluation session – Identifying themes from the previous weeks exploratory exercises

	Strongly agree				Strongly disagree
1. The session/s aims were clearly explained	1	2	3	4	5
2. The activities/presentations were relevant to the research	1	2	3	4	5
3. The researcher communicated well with the participants	1	2	3	4	5
4. The session/s activities enabled you to share your views	1	2	3	4	5
5. The session/s activities enabled you to share your views	1	2	3	4	5
6. I was able to learn about health and benefit from the session/s	1	2	3	4	5
7. I would be interested in attending a follow-up session	1	2	3	4	5
8. I would be interested in taking part in phase 2	1	2	3	4	5

8. Given the research question, was this consultation: ❑ a. Too short ❑ b. Right length ❑ c. Too long

9. Please rate the following:

	Excellent	Very Good	Good	Fair	Poor
a. Materials	❑	❑	❑	❑	❑
b. Meeting space	❑	❑	❑	❑	❑
c. Lunch	❑	❑	❑	❑	❑
d. The program overall	❑	❑	❑	❑	❑

12. What did you most appreciate/enjoy/think was best about the consultation? Any suggestions for improvement or further activities?

_____

_____

_____

_____

[redacted] Group

Thank you!

Appendix 3 - Sample of each table register - Register and coded allocations

Table A Code Assigned	Name	Gender	Ethnicity	Age group 18-39 40 -69 70 - 85	Profession/role
A1					
A2					
A3					
A4					
A5					
A6					
A7					
A8					

Appendix 4 – Phase 1 Demographics

Table Number	A1	A3	A4	A5	A6	A7	A8
Age	40 - 69	40 - 69	40 - 69	40 - 69	40 - 69	40 - 69	40 - 69
Gender	Female	Female	Female	Female	Female	Female	Female
Ethnicity	Black African	Black British	British Caribbean	African	Caribbean	African	African

Table Number	B1	B2	B3	B4	B5	B8
Age	40 -69	40 - 69	40 - 69	40 -69	70-85	40 - 69
Gender	Male	Female	Female	Male	Female	Female
Ethnicity	Black Caribbean	African	Caribbean	Black British	West Indian	British Jamaican

Table Number	C1	C3	C4	C5	C6	C7
Age	18 -39	40 -69	40 - 69	40 - 69	40 - 69	70 -85
Gender	Male	Female	Female	Female	Female	Female
Ethnicity	Black British	Jamaican	Jamaican	British Jamaican	British Jamaican	Jamaican

Table Number	D1	D3	D4	D5	D6
Age	40 -69	40 – 69	40 - 69	40 - 69	40 - 69
Gender	Female	Female	Male	Female	Female
Ethnicity	Black African	British Caribbean	British Caribbean	Nigerian	African

Table Number	E1	E2	E4	E5	E6	E8
Age	40 -69	70- 85	70 - 85	40 -69	18 - 39	40 – 69
Gender	Female	Female	Female	Male	Female	Male
Ethnicity	Black African	Caribbean Barbadian	Jamaican	Nigerian	Black British Jamaican	African Nigerian

Table Number	F1	F2	F3	F4	F5	F6	F7
Age	40 -69	40 - 69	40 - 69	18 - 39	18-39	40 – 69	18-39
Gender	Female	Male	Female	Female	Male	Female	Female
Ethnicity	Nigerian	West Indian	Black Jamaican background	Black British Jamaican	Black Jamaican	British Jamaican	British Jamaican

Appendix 5 - Phase 2 Focus Group Overview

Phase 2 Focus Group – What Matters to you? What's on your mind, why do I want to do this?

Introduction to Phase 2

Participants of African and African Caribbean descent were called to take part in a collaborative research intervention to explore ways to identify access to health for the Black community. The aim of this phase is to give 'space' to the voices of the participants where their lived experience, their perceptions of health and the factors that impact upon their day-to-day health decisions can be examined.

A closed community forum consisting of 6-8 individuals from phase 1 of the study will be created.

Some activities negotiated and agreed with the participants.

Reminder of Objectives

1) To examine user perspectives of the factors that impact upon the incidence and prevalence of CVD for people of African and Caribbean descent
2) To establish the subject groups' knowledge of CVD, risk and its prevention and to identify how this impact upon engagement in health and well-being activities
3) To explore the factors that impact upon the ability of the African and Caribbean community to engage in CVD preventative health behaviours
4) To develop appropriate and tailored health care interventions to reduce health disparities within this community

Present findings from phase 1

The aim is to unpack the findings below over the next sessions so that knowledge can be created to improve the health of African and Caribbean community. Highlight some key issues from phase 1 below

1) The community needs are judged and formed by the implicit biases of gatekeepers.

2) Individuals do not feel valued as the research and policy agenda is not inclusive of their needs. They believe that their health is de-prioritised. This results in poor engagement with services.

3) The community feel disempowered and that power and control remain in the hands of the gatekeepers to large public and voluntary organisations. This is evident in the seed-corn funding they receive which does not enable sustainable service provision to meet the needs of their community.

4) That there is a lack of value attached to the cultural needs of the African and Caribbean Community and that this is about identities of the health seeker seen through the eyes of the gatekeepers.

Overall, the group echoed repeatedly the direct impact upon their health outcomes in terms of the level of poor culturally insensitive health care provision and the inadequate health prevention guidance that they receive

So what resources are needed in the African and Caribbean community to improve health

Appendix 5a - Phase 2 Focus Group Sessions

Focus group discussion – guide. What is it like accessing health care in GM?

Week 1 - Getting to know each other

- Started with cultural foods, rearranged tables and space. African Caribbean cloth on the tables
- Establish group rules
- Consent forms
- PIS
- Tape recorder
- Participants write or draw their ideas on leaves and they discuss them as they put them on the felt. This way everybody gets a say, puts their ideas down and the researcher that can be taken and analysed later.
- Collecting information about each other
- Some story telling about themselves and families

Week 2 - Further exploration of views and attitudes relating to public health documents from phase 1 in relation to their everyday practices and experiences.

- Food
- Started with a prayer
- Professionals/practitioners
- Engagement with services
- Health prevention practices
- Barriers
- The way participants view their own health and that of their family/community
- Approach to health and ill health, diagnosis
- Challenges
- Solutions

Homework - Participants asked to keep a food diary for 1 week to document kinds of food eaten

Week 3 - Feedback from last week – spoke a lot about stressors so wanted to focus on health effects

- Prayer
- Food brought by participants and shared
- Issues around culture and religious practices
- Fattening rooms
- Place of community and religion
- People taking information and not valuing community

Week 4 - How they went about their daily lives, how they viewed themselves, how they managed

- Lack of value – Introduced Henrietta Lacks
- Lack of priority funders – resource
- Disempowered community with lack of resources
- Race racism-discrimination in health and ongoing challenges

- Image of Black people
- Stereotypes, stigma
- Own health education

Week 5 – Own realities about the Black communities and practices

Feedback from last week – Wanted to discuss how they saw themselves and how they were viewed by others. Participants focused a lot on the way the community did things and perceived practitioner views

- Prayers
- Challenges in the Community
- Networks
- The community needs and decision - making.
- Individual and community resource issues
- Identities as health seekers as seen through the eyes of the gatekeepers
- Managing community demands/needs

Week 6 - Looking back at the discussions – Faye to bring summaries

- Putting phase 1 and 2 together – Looking and agreeing key issues from my summaries

General areas of discussion points from previous weeks – opportunities to add any other issues

Concluding the sessions

Appendix 6 – Ethical Approval

MANCHESTER METROPOLITAN UNIVERSITY
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE

M E M O R A N D U M

FACULTY ACADEMIC ETHICS COMMITTEE

Manchester Metropolitan University

To: Faye Bruce

From: [redacted]

Date: 16/06/2016

Subject: Ethics Application 1372

Title: An ethnographic study to explore and identify the 'hidden factors' that shape the everyday meaning of health for people of African and Caribbean descent: A CVD Focus.

Thank you for your application for ethical approval.

The Faculty Academic Ethics Committee review process has recommended approval of your ethics application. This approval is granted for 42 months for full-time students or staff and 60 months for part-time students. Extensions to the approval period can be requested.

If your research changes you might need to seek ethical approval for the amendments. Please request an amendment form.

We wish you every success with your project.

Appendix 7 - Introductory Letter to Phase 2

Dear Participant

Manchester Metropolitan University

Thank you for showing an interest in participating in what I call phase 2 of this study. You are invited to join a community of learning at a local venue and will be part of a group of approximately 8 people. Everyone who agrees to take part will be involved in weekly conversations and storytelling about the everyday practices that came out of the sessions you attended in phase 1. One of these activities will include looking more closely at the findings from the public health documents in phase 1 of the study and how the key issues affect your life. Other sessions may include a combination of everyday activities that require you to bring items to the forum so that the group can share everyday decisions that influence why you engage or do not engage in the things that impact upon your health.

The sessions will commence week beginning the 15th September 6.30pm and last on average 2 hours per week. The sessions will continue for a period of 6 weeks on the same day unless the group decides there is a better time. During the sessions, I will be recording and making notes. Cultural food will be provided during each session and I will be participating in activities and discussions with you.

In the pack you will find the participant information sheet for you to read and the consent form for you to sign and bring with you to the first session. If you have any questions, then please contact me on the number below or by email.

I look forward to confirmation of your participation using the telephone number on the phase 2 flyer below by Monday 5th September.

Appendix 8 – Participant Information Sheet

Manchester Metropolitan University

Participant Information Sheet
Date: 02 / 06 /2016

Research: A study to explore and identify the 'hidden factors' that shape the everyday meaning of health for people of African and Caribbean descent: A focus on cardiovascular diseases such as stroke and dementia and the risk factors such as high blood pressure, high cholesterol and diabetes.

This information sheet will:

- *Tell you what the study is about.*
- *Give you more detailed information about what will happen if you take part.*

Invitation – Phase 1

Thank you for reading this information sheet.
I would like to invite you to take part in my research study that is being undertaken to identify the lived experiences that impact upon the prevalence of cardiovascular disease such as stroke in the African and African and Caribbean community.

There are two parts to the study:
This part is phase 1 and will involve creating a forum whereby community members from the African and African and Caribbean community will cross-examine public documents around health conditions such as stroke.

The aim is to identify the usefulness of the health materials and to highlight any gaps that could directly impact on the everyday experiences of the participants.
Information gathered from the forums will be fed back directly to the researcher.

Phase two will involve the creation of a community of learning around health conditions such as stroke using the lived experiences and expert knowledge of the community participants.

Below is some important information that I would like you to read carefully before you make your decision to be involved or not so that you are fully aware of what is required. Please contact the researcher Faye if you need any further clarification using the contact details on page 5.

Manchester Metropolitan University

Participant Information Sheet
Date: 02 / 06 /2016

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Below is some important information that I would like you to read carefully before you make your decision to be involved or not so that you are fully aware of what is required. Please contact the researcher Faye if you need any further clarification using the contact details on page 5.

Purpose of the study

There are two reasons for this study, 1) is to collect data as part of my educational research for a doctoral degree and 2) to create a community where participants can build health knowledge to improve health.

Why have I been invited?

You have been invited because you are of African or African Caribbean descent and have lived experiences that could be explored to determine the factors that impact upon your health and health outcomes

Do I have to take part?

No. It is up to you to decide whether or not to take part. You can stop taking part in the study at any time, without giving a reason and your rights will not be affected if you decide not to take part or withdraw from the study All you need to do is contact me using any of the details below.

What will I have to do if I take part?

You will be invited to join an open group forum at a local community venue over four events lasting one and a half hours each. The group will spend time discussing and interrogating the health documents provided to see how they actually affect your lives.

What are the possible disadvantages and risks of taking part?

Participation in the study will require making your way to the destination and devoting a maximum of 1.5 hours per week over four weeks to the forum.

What are the possible benefits of taking part?

You will have the opportunity to share your views on public documents that will be communicated directly to policy makers via the researcher. Phase two of the study will provide further opportunity for participation in the research to equip you with the overall knowledge to build community capacity around health.

What happens when the research study stops?

You may want to join phase two of the study, if this is the case, you will receive an information sheet and be required to sign an additional consent form.

The research study is due to end in 2019 and the researcher will produce a PhD report, which includes the findings collected from the study. The plan is to publish the information and present the results of the research at conferences and within journals. Any interventions or recommendations resulting from the study will be shared with National Health Organisations such as Public Health England. The aim is to generate awareness among decision-makers located within health related organisations about the nature of cardiovascular disease for people of African and African Caribbean descent and to make recommendations for improvements in policy and health practices.

What if there is a problem?

If you have any concerns about taking part in the study, or would like to make a complaint, please contact me, these details are provided at the end of this sheet. If you decide to withdraw from the study, then the information you have provided to that point of withdrawal will be used, however, all personal contact details will be destroyed.

Will my taking part in this study be kept confidential?

Yes, all of your information will be treated with the strictest confidence and all legal and ethical considerations will be adhered to. You will be provided with ground rules regarding maintaining the confidentiality of other people's information and asked to sign a consent form agreement.

The information you provide will be audio recorded to help with analysing the data for the study. However, you will not be identified in the study and any comments you make will be anonymous. No one else will be involved in listening and analysing the data and the raw data from the tape recordings will be destroyed once it has been transcribed

All raw data will be kept safely and all computer stored information will be protected with a password only known to the researcher. No personal or organisational details revealing the participant will be included in any part of the study.

All data collected will be anonymised and it will not be possible to identify you during any part of the study and published work

Who is organising the research?

This research has been organised by Faye Bruce who is a Senior Lecturer and part-time PhD student at MMU. The researcher is also a registered general nurse and has

experience of cardiovascular health. The study has been approved by MMU where I am employed

What will happen to the results of the research study?

I will keep the anonymised notes and recordings I have undertaken for five years following the completion of the research study, after this time the notes and recordings will be destroyed safely. The anonymised study produced may enable us the researcher to submit the work for various publications as journal articles or further research opportunities in the future

Who has reviewed the study?

To protect participants, the study was submitted to Manchester Metropolitan University Ethical review of research process for approval, details of this are can be found at: http://www.mmu.ac.uk/staff/researchers/ethics.shtml.

Research Approval

Address: Faculty of Health, Psychology and Social Care
Manchester Metropolitan University
Brooks Building
53 Bonsall Street
Hulme
Manchester
M15 6BX
Telephone: 0161 247 2510
Email: f.bruce@mmu.ac.uk

If you are able to take part in the research please sign the consent form, which is attached. If you would like further information before deciding to take part please contact Faye who will answer any further questions you may have. You can ask for more time to make your decision.

Further information and contact details

If you require more information about this research please contact the following people:

Faye Bruce – Research Student
Professor Rebecca Lawthom – Director of studies
Dr Ornette Clennon – Research Supervisor

Faye Bruce Faculty of Health, Psychology and Social Care Manchester Metropolitan University	**Professor Rebecca Lawthom** Faculty of Health, Psychology and Social Care Manchester Metropolitan University Brooks Building	**Dr Ornette Clennon** Faculty of Health, Psychology and Social Care Manchester Metropolitan University

Appendix 9 – Consent Forms – Phase 1 & 2

Date: 2nd June 2016
Name: Faye Bruce
Course: PhD
Department: Health Professions
Building: Brooks
Manchester Metropolitan University
Tel: 0161 247 2510

Consent Form – Phase 1

Research: A study to explore and identify the 'hidden factors' that shape the everyday meaning of health for people of African and Caribbean descent: A focus on cardiovascular related diseases such as stroke, dementia and diabetes.

Name of Researcher: Faye Bruce

Participant Identification Code for this project:
Please initial box

1. I confirm that I have read and understood the information sheet dated .....for the above project and have had the opportunity to ask questions about the interview procedure. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my rights or care being affected ☐
3. I understand that my responses will be sound recorded and used for analysis for this research project. ☐
4. I give permission for my interview recording to be archived as part of this research project, making it available to future researchers. ☐
5. I give permission for use of anonymised quotations in publications ☐
6. I understand that my responses will remain anonymous. ☐
7. I agree to take part in the above research project. ☐
8. I understand that at my request a transcript of my interview can be made available to me. ☐

Name of Participant	Date	Signature
Faye Bruce Researcher	Date	Signature

To be signed and dated in presence of the participant

Once this has been signed, you will receive a copy of your signed and dated consent form and information sheet by post.

Date: 2nd June 2016
Name: Faye Bruce
Course: PhD
Department: Health Professions
Building: Brooks
Manchester Metropolitan University
Tel: 0161 247 2510

Consent Form – Phase 2

Research: A study to explore and identify the 'hidden factors' that shape the everyday meaning of health for people of African and Caribbean descent: A focus on cardiovascular related diseases such as stroke, dementia and diabetes.

Name of Researcher: Faye Bruce

Participant Identification Code for this project:
Please initial box

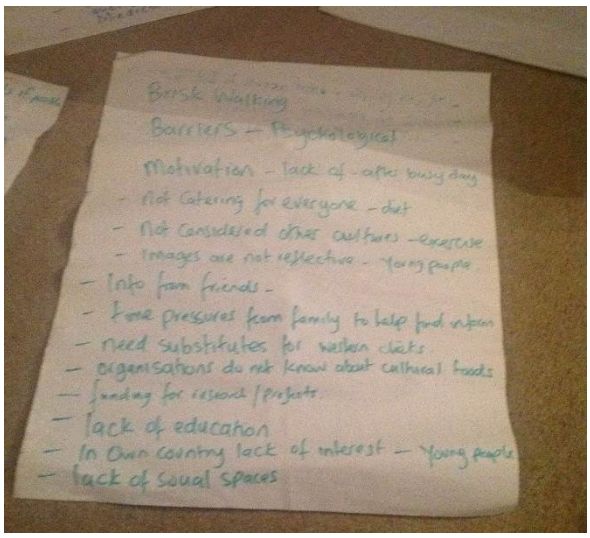
1. I confirm that I have read and understood the information sheet dated .....for the above project and have had the opportunity to ask questions about the interview procedure. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my rights or care being affected ☐
3. I understand that my responses will be sound recorded and used for analysis for this research project. ☐
4. I give permission for my interview recording to be archived as part of this research project, making it available to future researchers. ☐
1. I give permission for use of anonymised quotations in publications ☐
2. I understand that my responses will remain anonymous. ☐
3. I agree to take part in the above research project. ☐
4. I understand that at my request a transcript of my interview can be made available to me. ☐

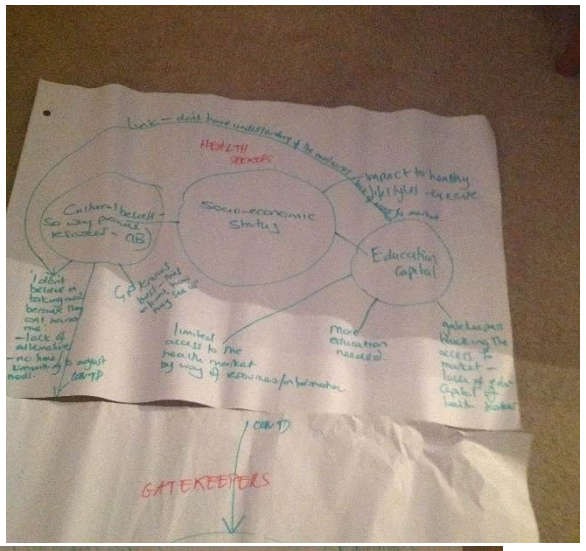
Name of Participant	Date	Signature
Faye Bruce Researcher	Date	Signature

To be signed and dated in presence of the participant

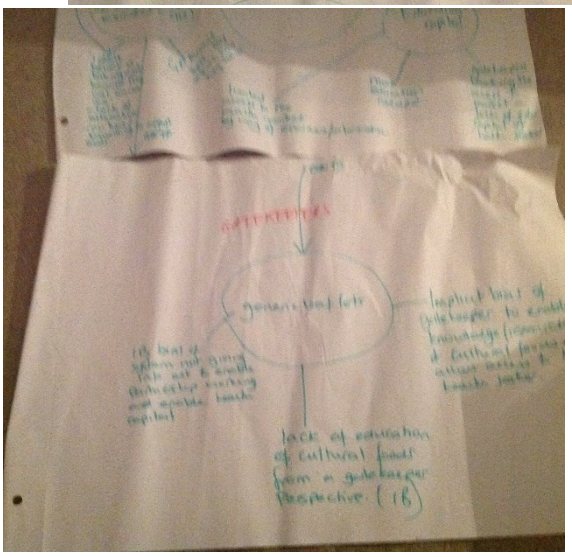
Once this has been signed, you will receive a copy of your signed and dated consent form and information sheet by post.

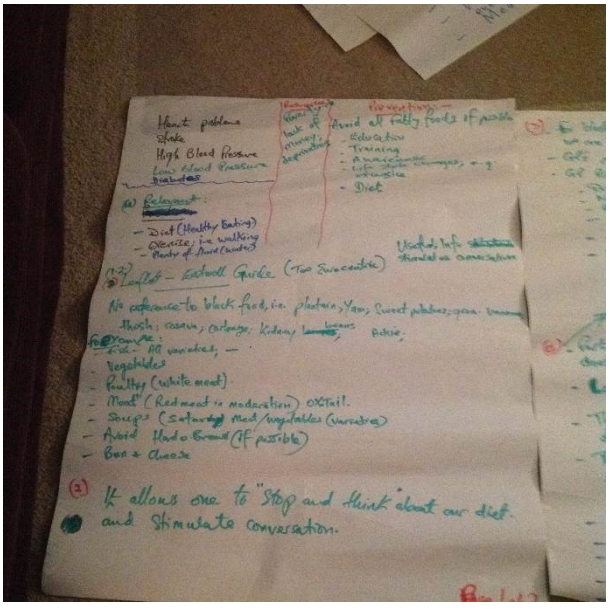
Appendix 10 – Some Phase 1 Flipchart Sheets



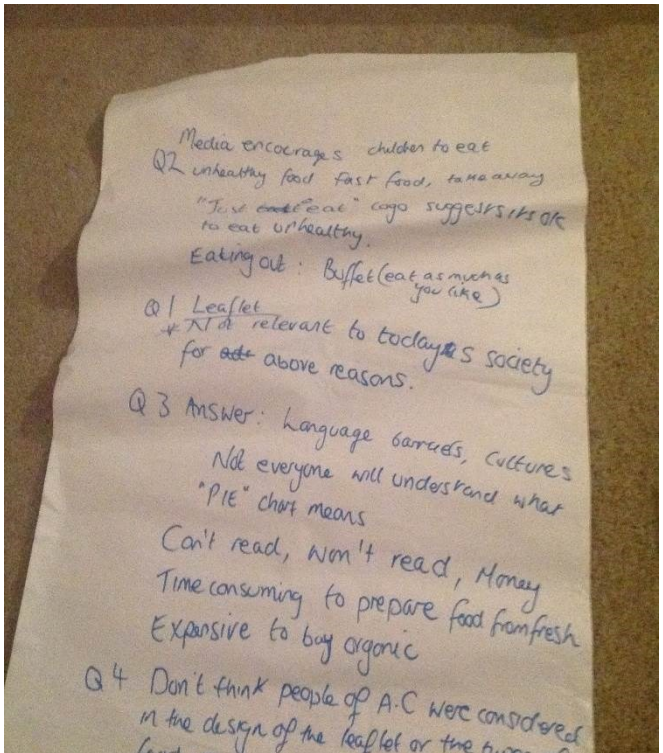


One of the participant tables

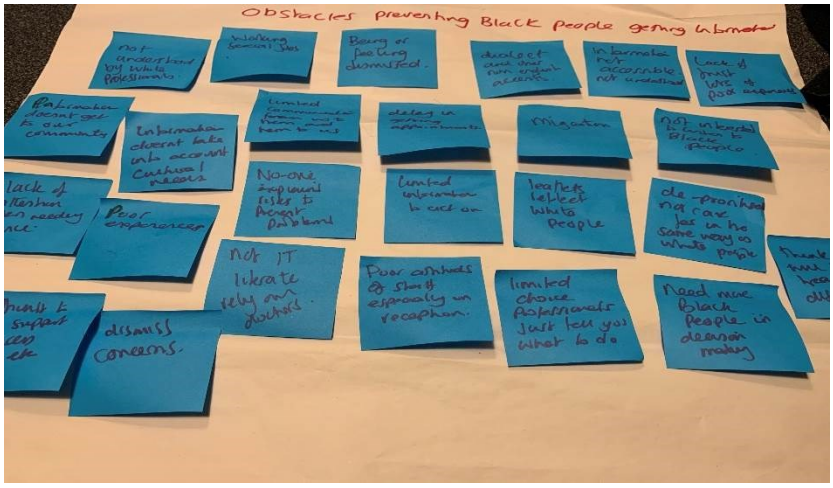


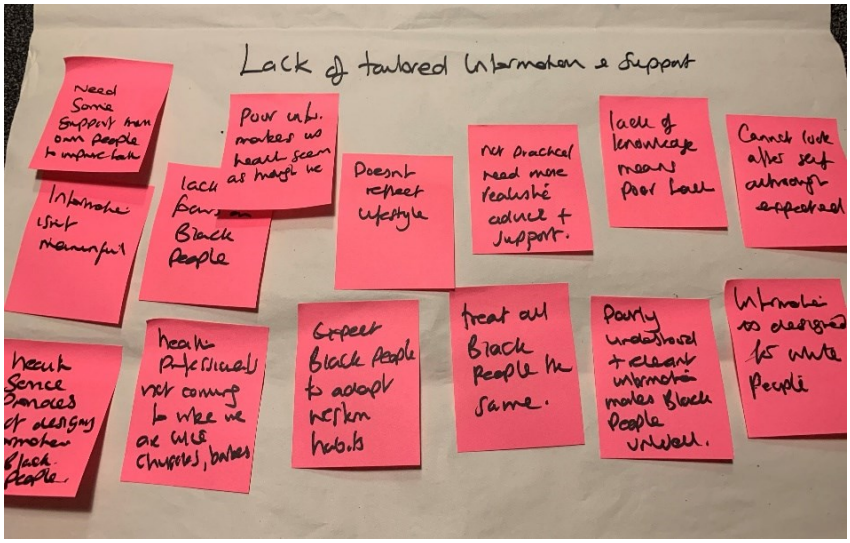


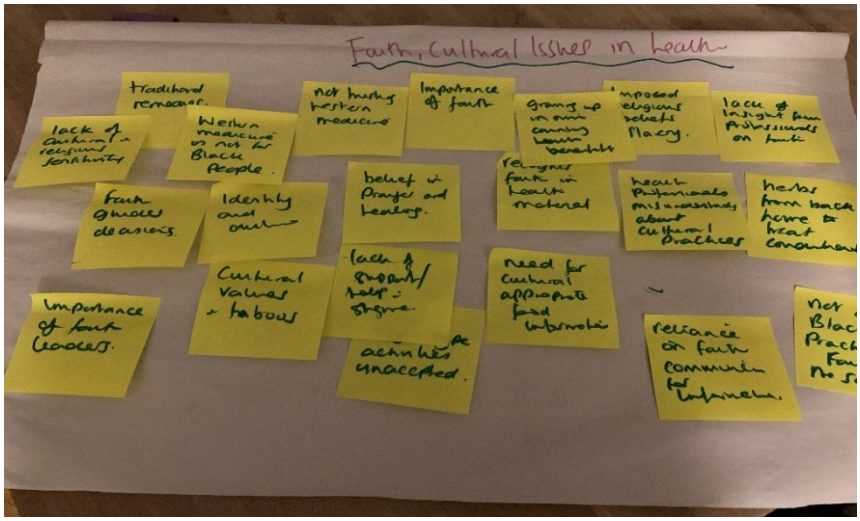
Appendix Snapshots of some key-points from participants



Appendix 11 Some early thematic analysis of phase 1

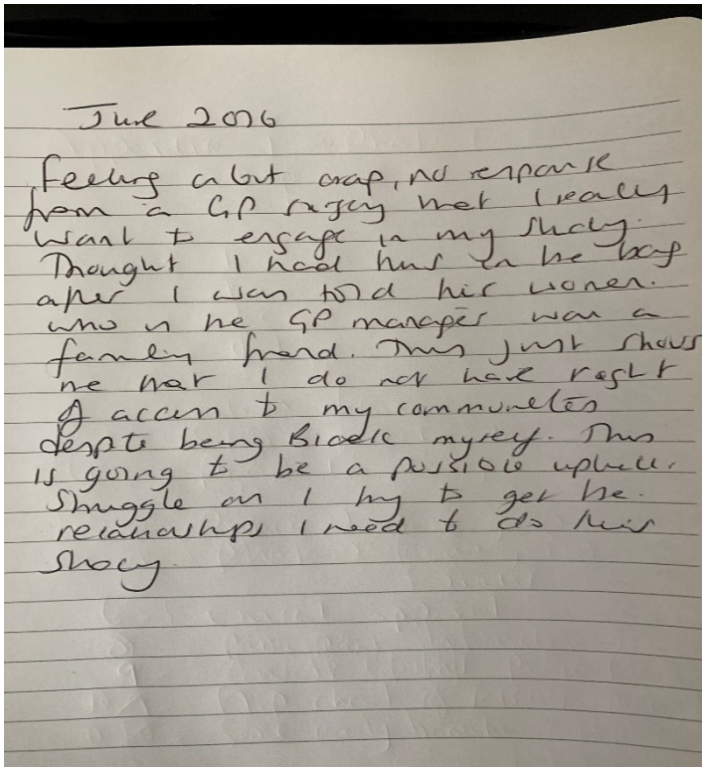






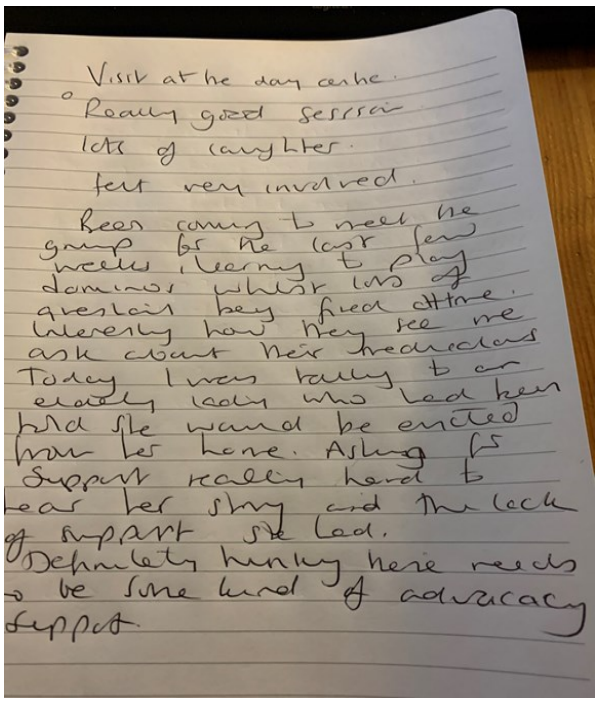
Appendix 12a – Some Fieldnotes

Pre-Phase - Homework


June 2016

Feeling a bit crap, no response from a GP agency that I really want to engage in my study. Thought I had hurt to be kept after I was told her worker who is the GP manager was a family friend. This just shows me that I do not have right of access to my communities despite being Black mixed. This is going to be a massive uphill struggle and I try to get the relationships I need to do this study.

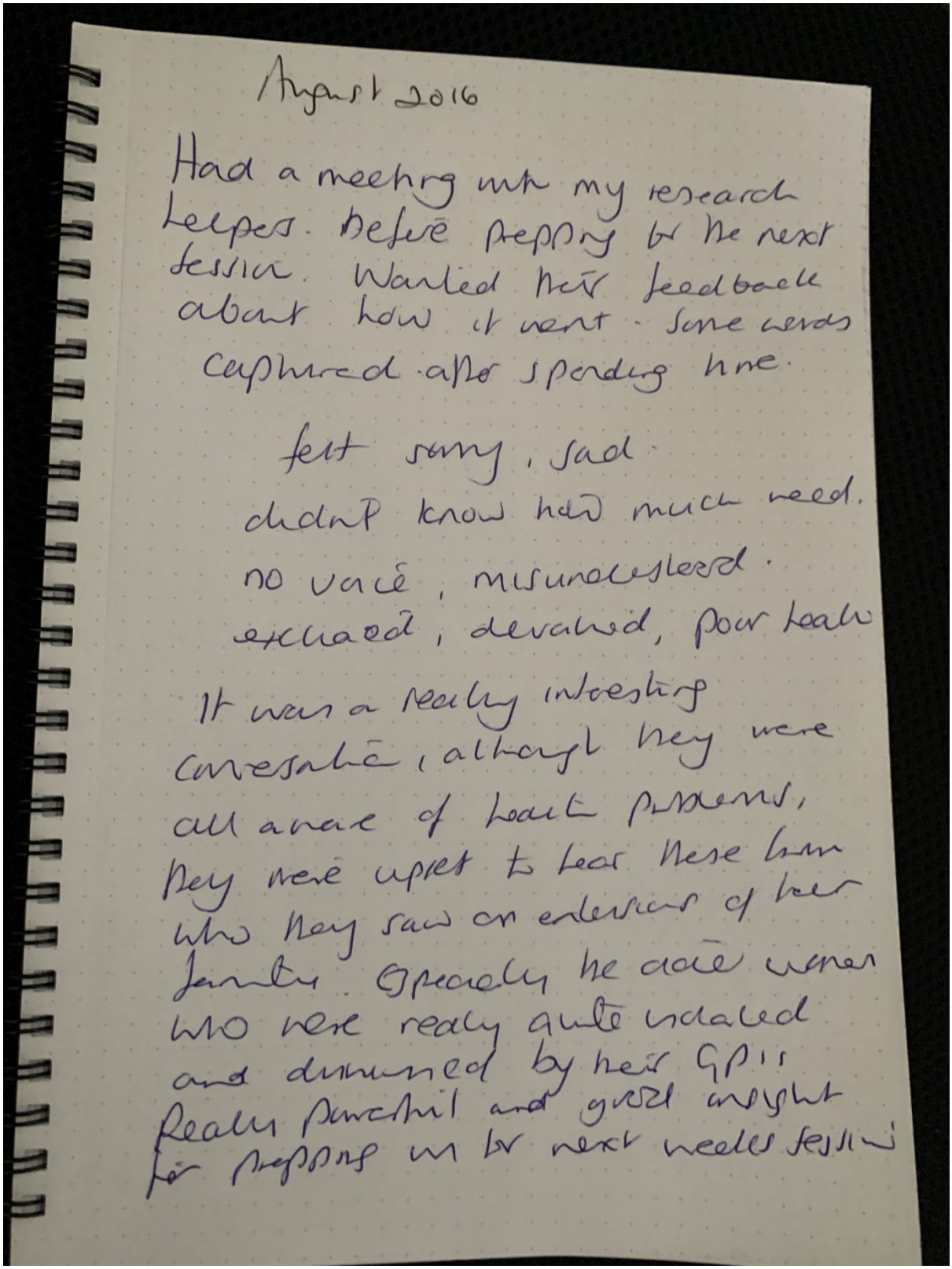
Appendix 12b - Pre-Phase – Pre- Phase relationship building - A visit to the day centre


Visit at the day centre.
- Really good session
- lots of laughter.
- felt very involved.

Been coming to meet the group for the last few weeks, learning to play dominos whilst lots of gossip being fired at me. Interesting how they see me ask about their headaches. Today I was lucky to see really lady who had been told she would be excited from her home. Asking for support really hard to hear her story and the lack of support she had.

Definitely thinking here needs to be some kind of advocacy support.

Appendix 12c – Debriefing with my Research Helpers

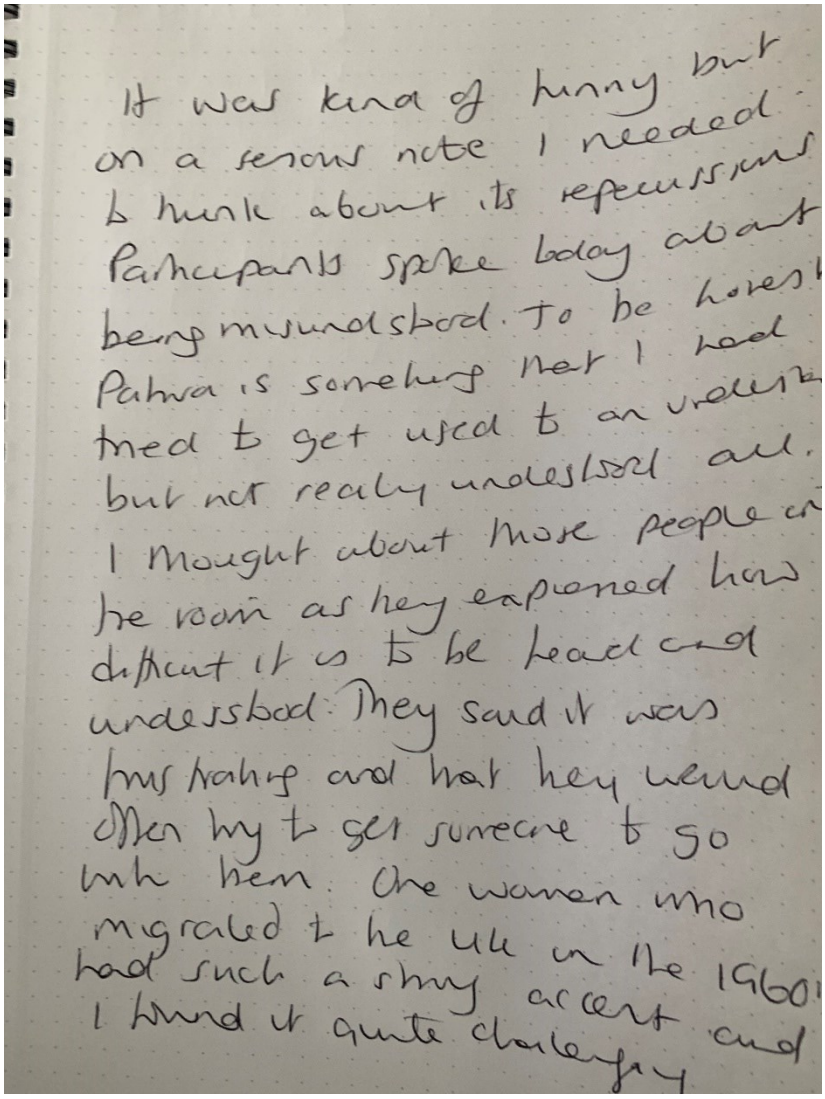

August 2016

Had a meeting with my research helpers. Before stepping in the next session. Wanted their feedback about how it went. Some words captured after spending time.

felt sorry, sad
didn't know how much need.
no voice, misunderstood.
exhausted, deprived, poor health

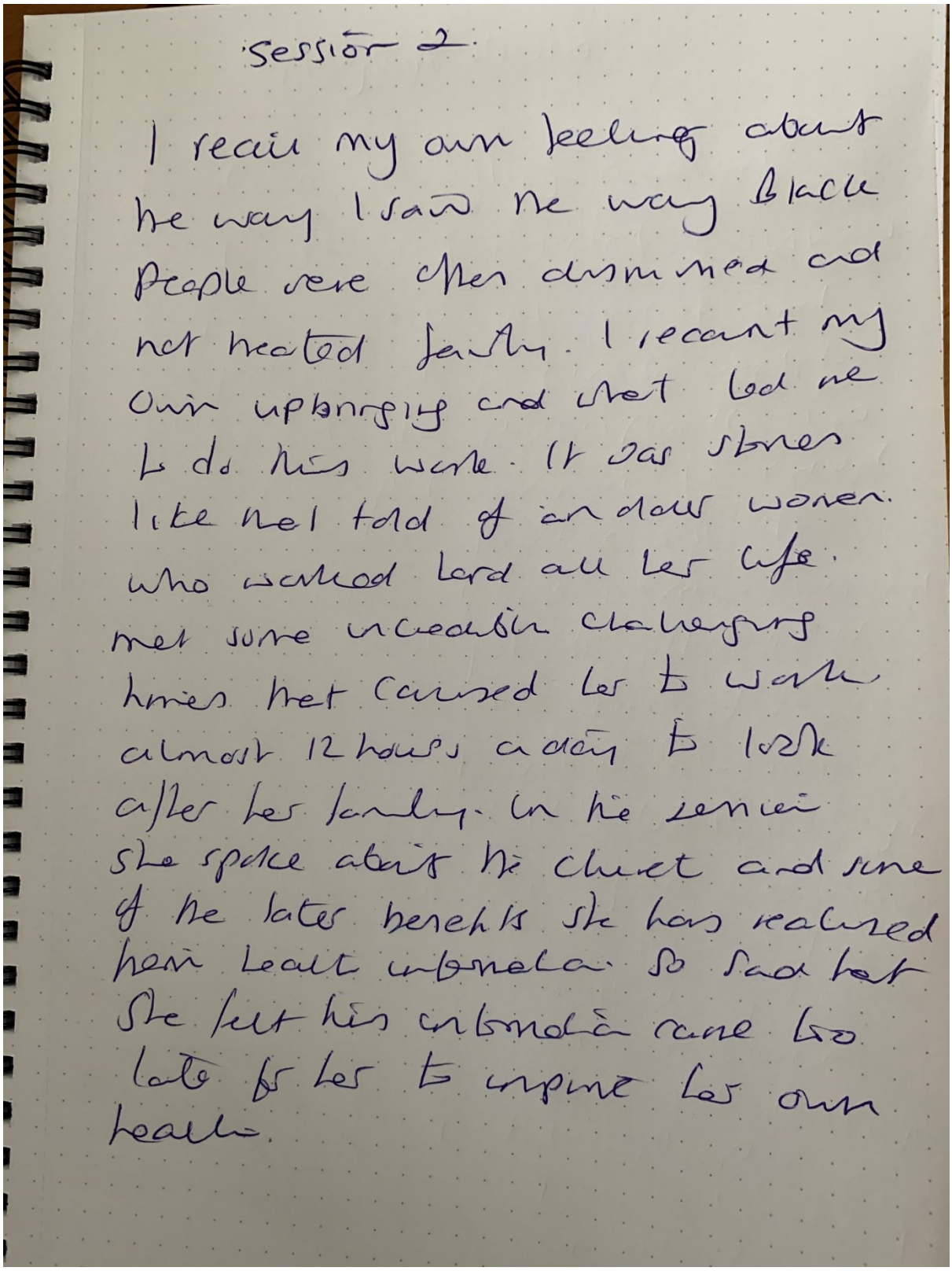
It was a really interesting conversation, although they were all aware of health problems, they were upset to hear these from who they saw on entrance of their journey. Especially the older women who were really quite isolated and consumed by their GP's. Really powerful and great insight for stepping in to the next needs session.

Appendix 12d – Reflections on the use of language in health care encounters



It was kind of funny but on a serious note I needed to think about its repercussions. Participants spoke today about being misunderstood. To be honest Patwa is something that I had tried to get used to and understand but not really understood at all. I thought about those people on the train as they explained how difficult it is to be heard and understood. They said it was frustrating and that they wanted offer my to get someone to go with them. One woman who migrated to the UK in the 1960s had such a strong accent and I found it quite challenging

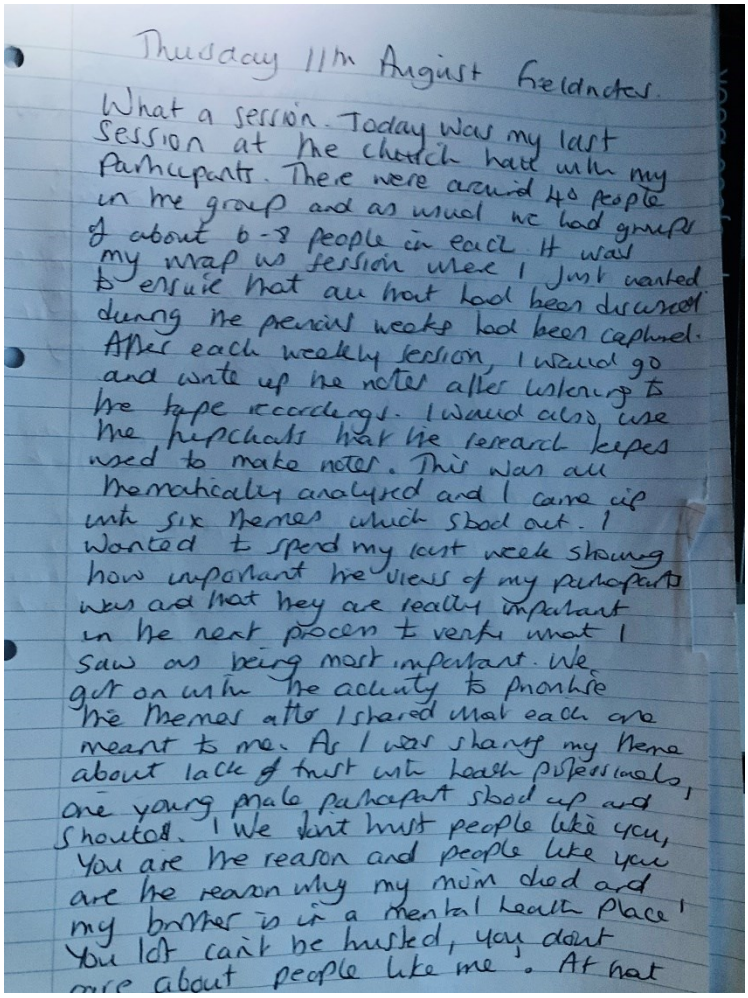
Appendix 12e – Reflections on a participant story – session 2



Session 2.

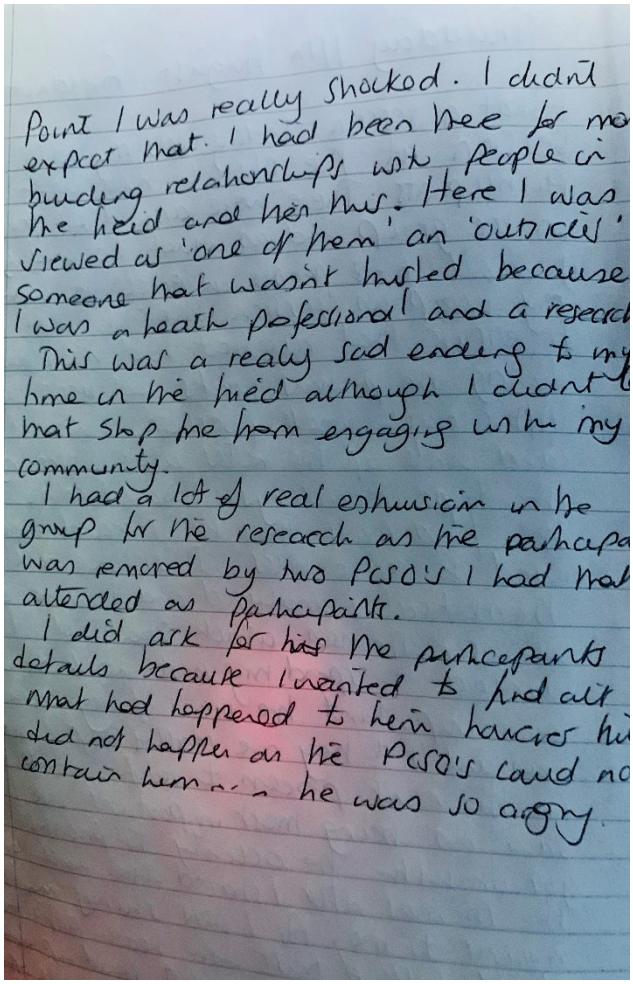
I recall my own feelings about the way I saw the way Black People were often dismissed and not treated fairly. I recount my own upbringing and what led me to do this work. It was stories like mine told of an older woman who worked hard all her life. met some incredible challenging times that caused her to work almost 12 hours a day to look after her family. In the session she spoke about the church and some of the later benefits she has received from Health insurance. So sad that she felt his information came too late for her to improve her own health.

Appendix 12e – An encounter with a participant – session 4



Thursday 11th August fieldnotes.

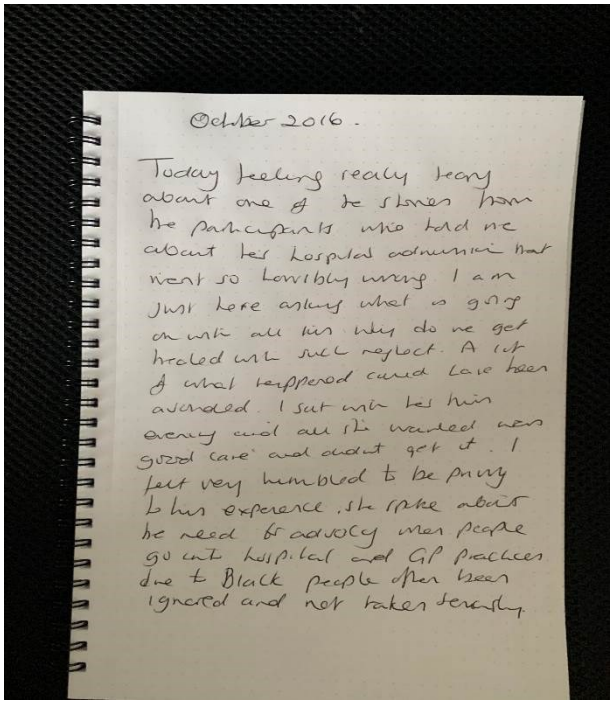
What a session. Today was my last session at the church hall with my participants. There were around 40 people in the group and as usual we had groups of about 6-8 people in each. It was my wrap up session where I just wanted to ensure that all that had been discussed during the previous weeks had been captured. After each weekly session, I would go and write up the notes after listening to the tape recordings. I would also use the flipcharts that the research keeper used to make notes. This was all thematically analysed and I came up with six themes which stood out. I wanted to spend my last week showing how important the views of my participants were and that they are really important in the next process to verify what I saw as being most important. We got on with the activity to prioritise the themes after I shared what each one meant to me. As I was sharing my theme about lack of trust with health professionals, one young male participant stood up and shouted. 'We don't trust people like you, You are the reason and people like you are the reason why my mum died and my brother is in a mental health place' You lot can't be trusted, you don't care about people like me'. At that



point I was really shocked. I didn't expect that. I had been here for nine months building relationships with people in the hood and her mum. Here I was viewed as 'one of them' an 'outsider' someone that wasn't trusted because I was a health professional and a researcher. This was a really sad ending to my time in the hood although I didn't let that stop me from engaging with my community.

I had a lot of real enthusiasm in the group for the research as the participants was removed by two PCSO's I had not attended as participants.

I did ask for his the participants details because I wanted to find out what had happened to him however this did not happen as the PCSO's could not contain him... he was so angry.



October 2016.

Today feeling really teary about one of the stories from the participants who told me about her hospital admission that went so horribly wrong. I am just here asking what is going on with all this why do we get treated with such neglect. A lot of what happened could have been avoided. I sat with her mum every visit all she wanted was good care and didn't get it. I felt very humbled to be privy to her experience. She spoke about the need for advocacy when people go into hospital and GP practices due to Black people often been ignored and not taken seriously.

Appendix 12g – Discussion with a participant – Phase 2

Appendix 13 – CAHN's launch event

Message from the Chair of Board of Directors

I am honored to be the Chair of the Caribbean and African Health Network Greater Manchester and to see the dream being realised here as we launch this Network. Today, we see the start of something Greater Manchester has not witnessed before, which is a partnership of collaborative working relationships across all sectors with a particular, but not exclusive, focus upon improving the health and wellbeing of the Caribbean and African Community.

Health and wellbeing inequalities across the Caribbean and African Community requires further attention. We recognise the work that has already begun, however, we do not underestimate the challenges faced as we strive to achieve improved holistic health and well-being in our community.

As we look around, we can see, hear and read the evidence about the inequities across many sectors to include education, criminal justice, housing, employment and others that impact upon the health and wellbeing of the community. This extends to the limited senior and strategic roles that people from Caribbean and African communities undertake in decision making and this needs to change.
Along with my Board of Directors, our goal is to work in mutual partnership and collaboration with all of our stakeholders and to develop strong and united working relationships with you our community to achieve CAHNs aims and objectives.

CAHN GM will work to safeguard our community and voluntary organisations and to empower them with the tools needed to sustain the health and wellbeing of the communities over the long term. Our partnerships are intergenerational and cross sectional and we will work creatively, innovatively and effectively to leave a legacy of improved health and wellbeing as the norm in our community.

We are pleased that you are able to join us and we hope that you enjoy the day and support our mission.

Appendix 14 - CAHN'S first press release

Press Release

For immediate release: 22.09.17

CAHN Greater Manchester (GM) Launch Event and Celebration of Black History

Event date: October 27th, 2017 at 09.30

CAHN aims to add healthier years to our community and ensure that we have a cutting edge response to identified public health needs.

Faye Bruce, Chair of CAHN and Senior Lecturer in Nursing at Manchester Metropolitan University states, "'Evidence points to worse health outcomes across almost every health indicator for people from the Caribbean and African Community". Therefore, CAHN exists to enable improved sustainable health and wellbeing for people on the ground. We seek to do this by influencing and advocating change to the prevailing systemic structures, policies and practices that have contributed to poor health within our community over the decades.

CAHN supported by Critical Race and Ethnicity Cluster at MMU, will be holding its signature event to celebrate the opening of our faith and community non-profit organisation. CAHN's launch features celebrations of Black History, with entertainment, presentations and lunch that reflects our culture.

The day will include attendance from Civic Leaders, speakers from across health, care and academic organisations, singers, poets and stalls.

The event will take place from 0930 – 1500 hrs
Friday 27th October 2017

The Longfords Suite,
Ryebank Road,
Chorlton
Manchester,
M21 9TA

ENDS

Notes to Editors

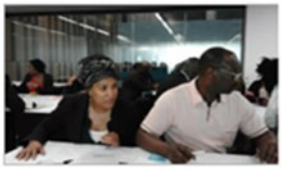
Contact: Faye Bruce – info@cahn.org.uk
Telephone number - 07946411197
Facebook page – https://www.facebook.com/groups/CAHNGM

Background information:

Appendix 15 – CAHNs journey from PhD data collection to gathering intelligence for Mary Seacole award

CAHN'S JOURNEY SO FAR

CAHN has been developed from a rich evidence base of community voices over two phases of a doctoral research study. It was here that the need to create a network of activity tailored to address the needs of the Caribbean and African Community were identified and actioned.



Faith and Community meetings

CAHN held three meetings between February and July 2017 with Caribbean and African faith and community organisations. We consulted on a number of initiatives to include Health and Wellbeing hubs, our community leadership programme and other initiatives.

CAHN received overwhelming support for the mission and direction of travel at this very early stage of our journey.

Appendix 16

DEVELOPING HEALTH LITERACY AMONG CARIBBEAN AND AFRICAN FAITH LEADERS TO INFLUENCE DECISION MAKING AT STRATEGIC LEVELS

OCTOBER 2018

MARY SEACOLE TRUST

FAYE BRUCE SENIOR LECTURER NURSING

REPORT LAUNCH IN THE HOUSES OF PARLIAMENT IN OCTOBER 2019

Appendix 16b

PROJECT REPORT LAUNCH & DISSEMINATION PLAN

The plan below gives an indication of how the project findings and learning will be disseminated in line with the dissemination and call to action in the report.

IMPACT ON POLICY, PRACTICE AND DISSEMINATION – CALL TO ACTION

My intention is that this report and the information contained within it, stimulates a discussion with policy makers here in Greater Manchester and NHS England. The intention is to move beyond the pilot to deliver a programme that can be relevant to a wider set of faith communities. It should end with action planning that can be written up and published to hold powerbrokers to account.

Aim

To disseminate findings from the Community Leadership Programme and put out a call to action.

Host

Further to conversations with Afzal Khan MP and his office, he has agreed to host the project report launch in Parliament in October.

Invitation List

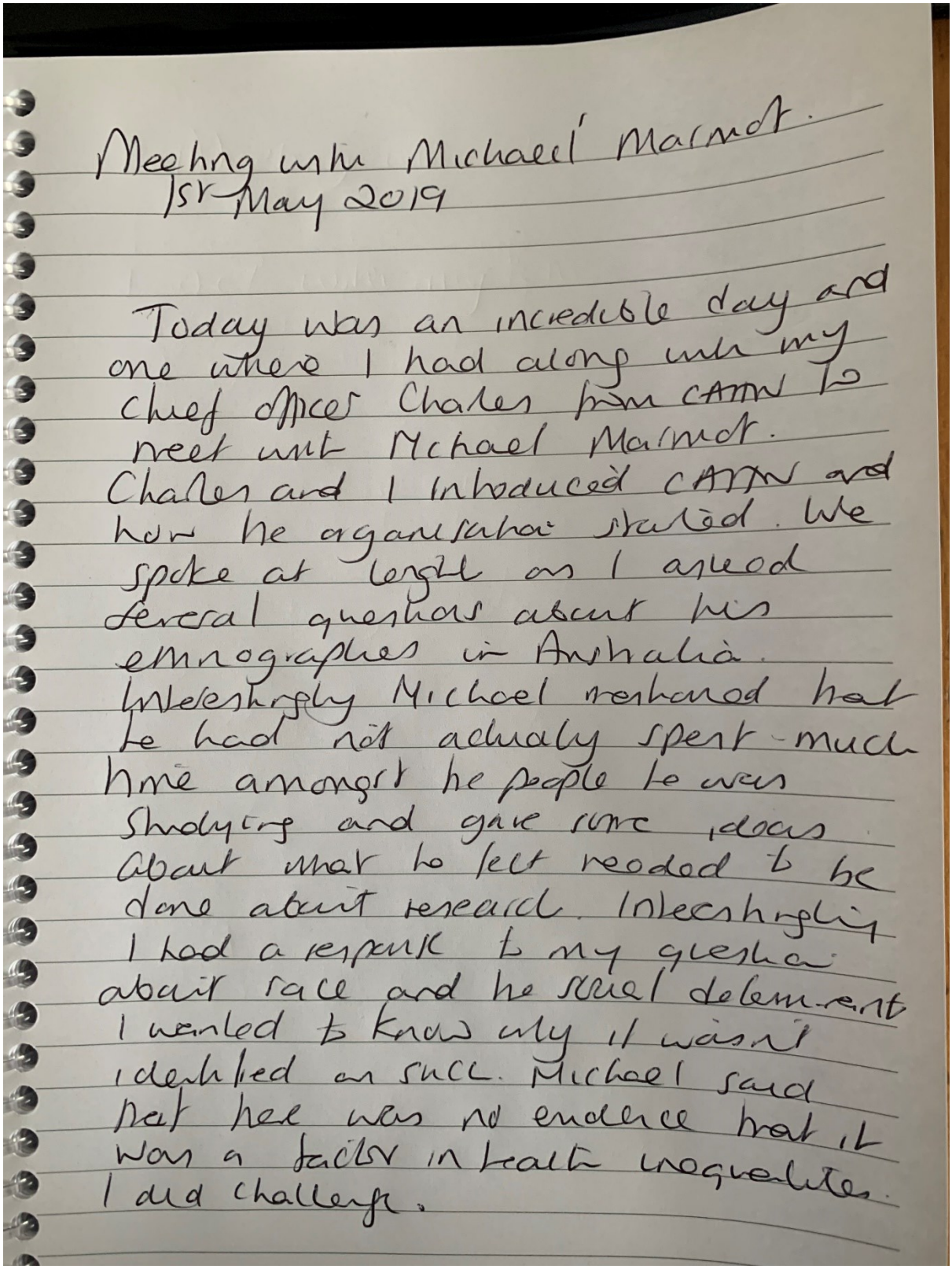
The Event Organiser and MP's office will invite

- Health Ministers as well as Equalities Ministers from both House of Commons and House of Lords.
- NHS England Leadership including Simon Stevens and Neil Churchill
- Race Disparity Unit
- Civic Leaders from London and Manchester
- Black Pentecostal Church Leaders including Bishop Joe Aldred (Ethnic Minority Lead at Churches Together in England), Pastor Agu Irukwu (Head of Redeemed Christian Church of God)

I propose to invite 6 participants from the Community Leadership Programme to London for the report launch. This will give leaders some exposure as well as opportunity for launch attendees to interact with contributors.

Appendix 17 - Reflections from Michael Marmot and CAHN Meeting in Manchester

Until the recent Marmot Review 10 years on (Marmot, 2020) there had been no discussion about race as a determinant of health



Meeting with Michael Marmot.
1st May 2019

Today was an incredible day and one where I had along with my chief officer Charles from CAHN to meet with Michael Marmot. Charles and I introduced CAHN and how the organisation started. We spoke at length as I asked several questions about his ethnographies in Australia. Interestingly Michael reframed that he had not actually spent much time amongst the people he was studying and gave more ideas about what he felt needed to be done about research. Interestingly I had a response to my question about race and the racial determinants I wanted to know why it wasn't identified as such. Michael said that there was no evidence that it was a factor in health inequalities I did challenge.